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IDENTIFIERS Epilepsy Foundation of America

ABSTRACT

These hearings are the second part of hearings on the kind of services children receive through charity; how charities obtain funds from the public; and how much they spend on fundraising, general management, and program services. The focus of these hearings is on the Epilepsy Foundation of America. Testimony was given by officials of that organization, a panel of medical experts, representatives of state agencies concerned with the regulation of children's charities, and a representative of the National Health Council. "Additional Information" and "Appendixes" consist of documents, statistics, and newspaper and periodical articles. In addition are appended statements from representatives of the Epilepsy Foundation of America, state regulatory agencies, medical experts, and the National Health Council. (JH)

ED 101030

CHILDREN'S CHARITIES, 1974

HEARINGS

BEFORE THE

SUBCOMMITTEE ON CHILDREN AND YOUTH

OF THE

COMMITTEE ON

LABOR AND PUBLIC WELFARE

UNITED STATES SENATE

NINETY-THIRD CONGRESS

SECOND SESSION

ON

EXAMINATION OF THE KIND OF SERVICES CHILDREN RECEIVE THROUGH CHARITY, HOW CHARITIES OBTAIN FUNDS FROM THE PUBLIC, AND HOW MUCH THEY SPEND ON FUND-RAISING, GENERAL MANAGEMENT, AND PROGRAM SERVICES

PART 2

EPILEPSY FOUNDATION

APRIL 8 AND 9, 1974

U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
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CHILDREN'S CHARITIES, 1974

MONDAY, APRIL 8, 1974

U.S. SENATE,
SUBCOMMITTEE ON CHILDREN AND YOUTH OF THE
COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 10 a.m., in room 4232, New Senate Office Building, Hon. Walter F. Mondale (chairman of the subcommittee) presiding.

Present: Senators Mondale and Stafford.

Committee staff present: Ellen Hoffman and A. Sidney Johnson III, professional staff members; Harvey Katz, consultant.

Senator MONDALE. The subcommittee will come to order.

This morning we continue our hearings on children's charities. This morning we will be hearing from officials of the Epilepsy Foundation of America, a panel consisting of Mr. Paul E. Funk, executive vice president; Thomas M. Ennis, executive director; H. Leroy Smith, controller; and Dr. David D. Daly, board of directors.

Will you please come to the witness table. I note that you have an exceedingly long statement, and a full statement will appear in the record as though read. I would hope that you could summarize and highlight what you regard to be important points, and the rest will appear in the record as an official part of this hearing. If you will, proceed.

**STATEMENT OF PAUL E. FUNK, EXECUTIVE VICE PRESIDENT,
EPILEPSY FOUNDATION OF AMERICA, ACCOMPANIED BY
THOMAS M. ENNIS, EXECUTIVE DIRECTOR; H. LEROY SMITH,
CONTROLLER; AND DAVID D. DALY, M.D., BOARD OF DIRECTORS,
A PANEL**

Mr. FUNK. Thank you, Mr. Chairman. I am particularly pleased to appear here today, not only because the Epilepsy Foundation is always happy to have an opportunity to illuminate the many and complex problems involved in the medical and social management of the epilepsies, but also because so many of the distinguished members of the Committee on Labor and Public Welfare have always been extremely helpful to us in many ways over the years, as we go about the task of interpreting the person with epilepsy and his needs to the society in which he lives.

Let me hasten to set your minds at ease. I will indeed highlight; I do not intend to read in its entirety the statement which has been submitted to the committee. The statement speaks for itself.

Senator MONDALE. As I said, that full statement will be in the official record, so none of it will be lost on the committee.

Mr. FUNK. But I do have some formalities to observe, and there are a few things I would like to say at this time. First the formalities.

As you have indicated, appearing with me today are Thomas M. Ennis, executive director and H. Leroy Smith Jr., controller of the foundation's staff. Statements from both are incorporated in the document submitted.

Senator MONDALE. Very well, they will appear as though read.

Mr. FUNK. Mr. Smith is a certified public accountant, and Mr. Ennis is a juris doctor. We are also honored to have with us David D. Daly, who is a medical doctor and president of the International League against Epilepsy, the worldwide organization of professionals in this field.

With your permission, we will testify as a panel.

I should also like to tell you that prior to preparing our statement we afforded copies of your letter to all of our 164 local chapters, to members of our national board of directors, and members of our National Professional Advisory Board, inquiring of these constituencies what information they would like to see included in the prepared statement.

Their suggestions have been incorporated, and the Executive Committee of the National Board of Directors, which held its regularly scheduled meeting on April 5 here in Washington, also reviewed the statement.

Epilepsy of course can strike anyone anytime. In about 75 percent of all cases it manifests itself before age 20, and for about two-thirds of these children and youth continues to be a problem to one degree or another, and in one way or another all of their lives.

We have been following these hearings with interest. We believe that there are at least four reasons why it is particularly appropriate for the Epilepsy Foundation to appear.

In the first place, voluntarism has always been a particularly American characteristic. It exists elsewhere in the world, but nowhere in the same manner and to the same extent as in this country. Foreign observers from de Toqueville up to the present have commented on this many times.

Important though voluntarism has been to our society in the past, we suspect that it has an ever greater role to play in the future. We have no shortage of problems. No one has all the answers. We are completely convinced that as the lines between the business sector, governmental sector and the volunteer sector blur and tend to merge, as our society makes a transition into the future, a future that as yet none of us can be entirely sure as to what it holds, these three sectors will be working more and more closely together.

We have a feeling that we may find clues during these hearings as to how they can work better together.

In the second place, there is significant legislation now before this chamber which deals with the epilepsies, and the Epilepsy Foundation of America, and I refer of course to Senate Joint Resolution 173, which calls for a National Commission on Control of Epilepsy and

its Consequences, to develop a detailed plan for coping with this age-old enemy of mankind "under the coordinating arm of the Epilepsy Foundation of America."

People with epilepsy and the epilepsy movement in the United States have been waiting for this legislation for 76 years, and we are confident that this time they will not be disappointed.

Third, we want to participate in the dialog and discussions now underway as to the ways in which, and the extent to which, organizations such as our own should report upon the activities and their finances to appropriate organs of our society.

As a leading voluntary health organization, we feel that we have some worthwhile contributions, suggestions, and recommendations to make. In our statement we have endeavored to illuminate the major national health problem by defining the kinds, causes, epidemiology, care and treatment of the epilepsies, for all EFA activities stem from the nature of the disorder with which we are concerned.

We have addressed ourselves to the history, growth and development of an increasingly effective advocate organization. We have described where and how the organization operates, the manner in which the views of our constituencies and citizen volunteers are translated into programs, and how those programs are budgeted and accounted for, and I have recommended that certain of these items such as "The Future of Voluntaries" and "The History of the Epilepsy Movement in the United States" go into the record.

Senator MONDALE. We will make those matters a part of the record unless they are too voluminous. In that event we will make them a part of the file.

Mr. FUNK. We have been as specific as we know how to be about the nature and cost of services provided, and the manner in which funding for them is presently secured.

We have made clear that in our view the first and perhaps the ultimately most important service a voluntary health movement can render patients is to make certain that their needs are properly interpreted to the society at large, and that vigorous advocacy leads to just and humane action on the part of that society.

Finally, we have addressed ourselves to recommendations which we believe might be helpful not only to EFA but to all similar organizations. Most important of these in our judgment is to point out the urgent need for one uniform financial report acceptable to all Federal and State jurisdictions, and all evaluative, rating and accrediting agencies.

There are a growing number of organizations I believe that are coming to essentially the same conclusions, including the Commission on Private Philanthropy and Public Needs in which Secretary of the Treasury George P. Shultz, John D. Rockefeller III, and Hon. Wilbur D. Mills are active.

We at the foundation have also addressed ourselves to this project, and with the help of our auditors, Price Waterhouse Co., have developed a draft form which I would like to submit to you today, and request that it be placed in the record of these hearings.

Senator MONDALE. Without objection it will be placed in the record.

[The draft form referred to follows:]

II

(Organization Name)

STATEMENT OF FUNCTIONAL EXPENSES

COMING 1962

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	PROGRAM SERVICES					MANAGEMENT AND GENERAL			
						Total Program Services	Management and General	Fund Raising	Total Supporting Services
Salaries									
Employee benefits									
Profit share									
Total salaries & related expenses									
Grants and Grants (A, B, C, D, E)									
Professional fees and consulting services									
Printing and publications									
Telephone and teletype									
Postage and shipping									
Equipment (rent, utilities, insurance, etc.)									
Furniture rental									
Local transportation									
Conferences, conventions, meetings									
Travel									
Site processing									
Office supplies									
Other, specify									
Total expenses before depreciation									
Depreciation expense (Schedule IV)									
Total expenses									

* Enter program name and complete Schedule VIII.

III

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(Organization Name)

STATEMENT OF FUNCTIONAL EXPENSES

NATIONAL OFFICE ONLY

	PROGRAM SERVICES					MANAGEMENT AND GENERAL				
	Total	Program	Supporting	Total	Total	Management	Fund	Total	Total	
office										
employee benefits										
rental taxes										
total salaries & related expenses										
rents and Grants (Schedule D)										
professional fees and consultant										
services										
printing and publications										
telephone and telegraph										
freight and shipping										
agency (rent, utilities,										
insurance, etc.										
equipment rental										
all transportation										
conferences, conventions, meetings										
rentals										
processing										
ice supplies										
if, specify										
total expenses before depreciation										
depreciation expense (Schedule VIII)										
total expenses										

to State Department and
Complete Schedule VIII

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(Organization Name)

MILWAUKEE

CITY OF MILWAUKEE

	UNRESTRICTED FUND				Land, Building and Equipment Fund			
	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended
ASSETS								
Cash								
Investments (S.A., L.S., E.)								
For long-term purposes								
Other receivable								
Prepaid expenses								
Grants receivable								
Inventory:								
Instructional materials								
Office supplies								
Other (specify)								
Accumulated depreciation on land, buildings and equipment								
Fixed assets (S.A., L.S., E.)								
Accumulated depreciation on (S.A., L.S., E.)								
Total assets								
LIABILITIES								
Accounts payable and accrued expenses								
Research grants payable (S.A., L.S., E.)								
Mortgage payable: current portion								
Mortgage payable: long-term portion								
Contributions designated for future								
Other (specify)								
Total liabilities								
FUND BALANCE								
Restricted:								
Group								
Other (specify)								
Designated (specify)								
Land, building and equipment:								
Investment								
Interpreted - restricted								
Endowment								
Undesignated								
Total fund balance								
Total liabilities and fund balance								

MILWAUKEE

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(Organization Name)
BLAKE HOUSE
 NATIONAL OFFICE ONLY

	UNRESTRICTED		RESTRICTED		Land, Building and Equipment Fund		Endowment Fund	
	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended	Year Ended
ASSETS								
Cash								
Investments: (I.L.D.J. ☒)								
For long-term purposes								
Other								
Pledges receivable								
Accounts receivable								
Grants receivable								
Inventory								
Construction materials								
Direct mail materials								
Other (specify)								
Accrued interest, other receivable								
Prepaid expenses								
Pledges payable (I.L.D.J. ☒)								
Accumulated depreciation (I.L.D.J. ☒)								
TOTAL ASSETS								
LIABILITIES								
Accounts payable and accrued expenses								
Research grants payable (I.L.D.J. ☒)								
Mortgage payable: current portion								
Mortgage payable: long-term portion								
Contributions designated for future periods								
Other (specify)								
Total liabilities								
NET WORTH								
Restricted:								
For long-term purposes								
Other (specify)								
Designated (specify)								
Land, building and equipment:								
Depreciated								
Undepreciated - restricted								
Endowment								
Undesignated								
Total fund balance								
Total liabilities and fund balance								

SCHEDULE OF PUBLIC SUPPORT

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[illegible]

VII

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(Organization Name)
SCHEDULE OF REVENUE

	COMBINED				NATIONAL OFFICE ONLY					
	Current Funds		Land Building & Equipment		Current Funds		Land Building & Equipment		Totals	
	Unrestricted	Restricted	Unrestricted	Restricted	Unrestricted	Restricted	Unrestricted	Restricted	Current Year	Prior Year
1. Investment income: Interest income Dividend income Other investment income	0	0	0	0	0	0	0	0	0	0
2. Net gain on sale of investments										
3. Fee income: a. Membership fee and dues b. Subscription fee c. Client service fee d. Other fee										
4. Special service and sales of merchandise (i.e., VIII)										
5. Other revenues: a. Net gain on sale of assets b. Rental income c. Other										
6. TOTAL REVENUES										

XII

(Organization Name)

**SCHEDULE OF CHANGES TO LAND, BUILDINGS
AND EQUIPMENT AND ACCUMULATED DEPRECIATION**

Line 8-103

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	Balance at / /	Additions (Note 1)	Retirements or Sales	Other	Balance at / /
<u>Land, Buildings and Equipment</u>					
Equipment & Furniture	\$	\$	\$	\$	\$
Buildings					
Leasehold improvements					
Other, specify _____					
Total depreciable assets					
Land					
Total land, buildings and equipment	\$	\$	\$	\$	\$

<u>Accumulated Depreciation</u>					
Equipment & Furniture	\$	\$	\$	\$	\$
Buildings					
Leasehold improvements					
Other, specify _____					
Total accumulated depreciation	\$	\$	\$	\$	\$

NOTE 1	ADDITIONS		
	Cost	Donated Value	Total
Equipment & Furniture	\$	\$	\$
Buildings			
Land			
Other, specify _____			
Totals	\$	\$	\$

(Organization Name)

VIII

**SCHEDULE OF CHANGES TO LAND, BUILDINGS
AND EQUIPMENT AND ACCUMULATED DEPRECIATION**
NATIONAL OFFICE ONLY

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	Balance at / /	Additions (Note 1)	Retirements or Sales	Other	Balance at / /
<u>Land, Buildings and Equipment</u>					
Equipment & Furniture	\$	\$	\$	\$	\$
Buildings					
Leasehold improvements					
Other, specify					
<u>Total depreciable assets</u>					
<u>Land</u>					
<u>Total land, buildings and equip- ment</u>	\$	\$	\$	\$	\$

<u>Accumulated Depreciation</u>					
Equipment & Furniture	\$	\$	\$	\$	\$
Buildings					
Leasehold improvements					
Other, specify					
<u>Total accumulated depreciation</u>	\$	\$	\$	\$	\$

NOTE 1	ADDITIONS		
	Cost	Donated Value	Total
Equipment & Furniture	\$	\$	\$
Buildings			
Land			
Other, specify			
<u>Totals</u>	\$	\$	\$

XIV

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(Organization Name)
 SCHEDULE OF CHANGES IN RESERVE

Description of Reserve	Fund	Balance Beginning of Year	Additions to Reserve	Deductions from Reserve	Balance End of Year
National Office Only Reserve for uncollectible pledges					
Local Affiliates Reserve for uncollectible pledges					
Combined total					

SCHEDULE OF EXECUTIVE COMPENSATION
 IN EXCESS OF \$30,000

XV

Name, Social Security No., Title & Address	Time Devoted to Position	Annual Compensation
		0

(Organization Name)

XVI

SCHEDULE OF PROFESSIONAL FEESIN EXCESS OF \$30,000

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Name and Address	Type of Service	Amount Paid

(Organization Name)XVIIIDESCRIPTION OF PROGRAM SERVICES**BEST COPY AVAILABLE**

Program	Description

(Organization Name) _____

ORGANIZATION DATA PROFILE

YEAR ENDED _____

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1. Organization's name and address: 2. Chief executive's name and address:

_____	_____
_____	_____
_____	_____

3. If financial records kept at address other than address listed in (1) above, give address and name of custodian.

4. Date organization began operations _____.
5. Form of organization is: Corporation _____; partnership _____; individual _____; trust _____; other _____, explain.

6. State of domicile _____.

7. Number of affiliates _____. (Attach list of names, addresses and dates of affiliation).

8. During the past year, have there been any amendments to the organization's by-laws? _____; changes in the form of organization? _____; changes in the five highest paid executives? _____.

9. How many meetings were held last year for:

Governing Board _____

Executive Committee _____

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10. Average number of persons attending meetings:
Governing Board _____
Executive Committee _____
11. Do any Board members receive salaries? _____. Are expense accounts or other remuneration in any form paid to or provided Board members? _____. If yes, attach explanation.
12. Attach list of names and addresses of directors.

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(Organization Name) _____

FINANCIAL AND REGULATORYDATA PROFILEYEAR ENDED _____

1. The organization's accounting period is a calendar year _____ or fiscal year _____. If fiscal year, the year ends on _____.
2. The organization's financial statements are prepared on the cash _____ or accrual _____ basis of accounting.
3. Name and address of independent accountants:

4. Has the organization changed independent accountants during the past year? _____. If yes, attach explanation and name and address of former independent accountants.
5. Has the organization obtained a ruling that it is exempt from Federal income taxes? _____. If yes, date of exemption letter is _____ and Internal Revenue Code section under which exempt is _____.
6. Has tax exemption been denied or cancelled at any time? _____. If yes, attach explanation.
7. Is the organization duly registered in all states in which funds are solicited and registration is required? _____. Have all the registration fees been paid? _____. If "no" to either question, attach explanation.
8. Has a license, permit or registration been denied or revoked by any governmental agency or are proceeding pending therefor? _____. If yes, attach explanation.

- 2 -

9. Has the organization been enjoined from soliciting contributions or are proceedings pending therefor ? _____. If yes, attach explanation.

Mr. FUNK. We favor a detailed uniform report because the Epilepsy Foundation of America wants there to be no mistake about what it is, what it does, how it operates, how it raises funds, and how it expends those funds.

Mr. Chairman, my colleagues and I would now be pleased to respond to your questions.

Senator MONDALE. Mr. Ennis, I understand that you are the executive in charge of fundraising. Has this always been your chief responsibility with the Epilepsy Foundation?

Mr. ENNIS. No, Mr. Chairman. At various times my duties and assignments have changed depending upon the needs of the foundation, and at the latter part of last year I became in charge of the fundraising areas. At other times I have worked with chapters, the Professional Advisory Board, and substantive programs matters.

As you realize, when we were small we in a sense had more duties to cover in terms of assignment.

Senator MONDALE. For how long have you been with the foundation?

Mr. ENNIS. Mr. Chairman, I have been there 7½ years. I came in the fall of 1966.

Senator MONDALE. What did you do before coming there?

Mr. ENNIS. I was with Project Hope, the international medical foundation in an administrative position, as director of development, again a rather broad spectrum of duties.

Senator MONDALE. Were you in fundraising?

Mr. ENNIS. Yes. Right.

Senator MONDALE. Did you have anything to do with the foundation's fundraising before assuming full responsibility for this activity?

Mr. ENNIS. At various times we had department heads that were specifically involved in the operation, and I would sometimes have an overview responsibility.

Senator MONDALE. How much of your time would you say was devoted to fundraising in the year 1972?

Mr. ENNIS. In 1972?

Senator MONDALE. Yes.

Mr. ENNIS. In 1972 I would think probably maybe 15 or 20 percent.

Senator MONDALE. What else did you do for them in 1972?

Mr. ENNIS. I was involved in activities with a professional advisory board, the chapters, seminars, workshops, meetings with certain governmental activities such as developmental disabilities; travel to chapter seminars—rather broad activities, covering all the sectors of the foundation.

Senator MONDALE. Mr. Smith, can you give us a description of what your responsibilities are and tell us how long you have been with the foundation and where you worked before?

Mr. SMITH. Mr. Chairman, I am the controller, and my responsibilities cover the bookkeeping, and financial reports that are issued.

I have been with the foundation a little over 9 months. Prior to coming with the foundation I was vice president and treasurer of the H. L. Smith Co., which is my father's stock brokerage house.

Senator MONDALE. Mr. Funk, what are your responsibilities, as chief executive officer?

Mr. FUNK. Those are defined in detail in the bylaws of the organization, but perhaps can best be telescoped by saying that I am responsible for staff and for the implementation of board directives.

Senator MONDALE. How long have you been executive vice president?

Mr. FUNK. I have been executive vice president since December 1970. Prior to that time I was president. I have been chief executive officer for a total of 5 years.

Senator MONDALE. Were you with the foundation before that time?

Mr. FUNK. Let me elaborate a little bit if I may. I have been involved with the foundation for 12 years as a volunteer director, as chairman of its public information and education committee, as chairman of a unity committee which brought about merger of the predecessor organizations, as chairman of the program committee, and as president for two terms.

Senator MONDALE. All of those were staff positions, I gather?

Mr. FUNK. No, they were not. All of those positions, except for executive vice president were volunteer positions.

Senator MONDALE. As chief executive I assume you are aware of all aspects of the organization, and participate in a full range of all aspects of the operations.

Mr. FUNK. I do indeed.

Senator MONDALE. Are you more involved in some areas than in others?

Mr. FUNK. The area in which I am involved at any given time is apt to vary according to problems and opportunities with which we are confronted. I may be involved for a 3- or 4-month period, particularly heavy in updating consumer literature; currently I am much involved in a series of 10 movies.

The emphasis in front of me I would say varies throughout the year.

Senator MONDALE. Let us take 1973, the most recent year. What rough percentage of your time was spent on fundraising, would you say?

Mr. FUNK. I would estimate approximately 5 percent.

Senator MONDALE. Five percent?

Mr. FUNK. I would estimate that figure; yes.

Senator MONDALE. How much was that on community service?

Mr. FUNK. Community service would involve according to National Health Council standards, government liaison, would involve chapter development and other activities. If I had to pick a figure, I would say perhaps 25 percent.

Senator MONDALE. How much time then did you spend in general management of the organization?

Mr. FUNK. Time in general management, again, as defined by the standards—because the standards define that time spent in certain activities are chargeable to those activities—

Senator MONDALE. Correct.

Mr. FUNK [continuing]. Those defined in the standards as management in general, I would guess at 15 or 20 percent.

Senator MONDALE. That gives you about 45 percent. How do you spend the rest of your time?

Mr. FUNK. I spend time in research and professional education, and a great deal of time in public information and education.

Senator MONDALE. What percentage of your time would you have spent on fundraising in 1972?

Mr. FUNK. In 1972 I would again think about 5 percent.

Senator MONDALE. I understand the last audit of the foundation was for the year ending December 1972; is that correct?

Mr. FUNK. That is correct. A current audit is still in progress.

Senator MONDALE. And the financial statements that are contained in the 1972 annual report are a result of that audit.

Mr. FUNK. That is correct.

Senator MONDALE. This report shows that the foundation and its chapter raised \$4.1 million, and that the national office raised \$3.2 million of this. Can you tell us how the national office raises its money, how the chapters raise their money?

Mr. FUNK. The national office endeavors to secure funding in a variety of ways. This would include application for Government moneys; this would include solicitation of foundations and major donors. This would include the providing to chapters of fundraising materials and counsel.

This would involve working with social, civic, and fraternal organizations toward the end of their adopting epilepsy as a cause, and would very much involve direct mail solicitation of the general public.

Senator MONDALE. Can you give us the precise proportions of different income sources at the national level?

Mr. FUNK. The direct mail is the major source, and would be better than 90 percent. The others are relatively minor.

Senator MONDALE. How do the local chapters raise their money?

Mr. FUNK. The local chapters raise their money, and have in virtually every way known to man. At one time or another in one place or another the chapters have been successful with every form and in other places with the same forms have been not successful. Much depends upon the people leading the drive, their determination, their energy, and their position in the community.

Senator MONDALE. What is the most used form of fundraising at the local level?

Mr. FUNK. At the local level I believe I would say special events by which this could be anything from a cake sale to a walkathon, to a celebrity night, a sportsman dinner, and similar activities.

Senator MONDALE. In 1972 the national office and chapter spent their contributions in five types of program services. Are you devoting your resources to those same programs today?

Mr. FUNK. Yes, we are.

Senator MONDALE. I would like you to take each program service, and explain how that program works at both the chapter and the national level.

I would also like you to tell me the name and the title of the national staff person in charge of each program today, and in 1972.

Mr. FUNK. All right. If I may I would like to work from the annual report itself which classifies the activity by National Health Council standards.

Senator MONDALE. Surely.

Mr. FUNK. The first of these activities is research. This is an activity conducted only by national headquarters. The involvement of staff consists of publicizing the program, receiving applications from investigators, processing those applications for completeness and for conformity with standards established by our Professional Advisory Board, setting up meetings of the committee of the Professional Advisory Board, which evaluates the proposals, announcing the winners, making arrangements for the funding.

This activity is headed by Roger W. Buddington, Ph. D.

Public health education includes a wide variety of programs. Here we would have the preparation of TV messages, preparation of films, the operation of a film library, attendance at various professional conventions, new releases, the development of a wide variety of consumer pamphlets and professional literature, the manufacture of materials for a school alert program, the handling of epilepsy month which the President has proclaimed as National Epilepsy Month. That is in November—a wide range of similar activities.

In 1972 that department had two people involved. One was Robert H. Jones. One was Hugh Gage. The department is presently headed by Jame Gorman.

Professional education and training is, we believe, related to research in that one of the main functions here is to disseminate the latest research findings to doctors and to paraprofessionals and to practitioners of many professional disciplines. So these activities are also handled by Roger W. Buddington who I mentioned earlier was responsible for our research activities.

Community services by health council standards includes Government liaison, includes chapter development, and includes a number of other activities which for us one of the major elements would be our financial support of the National Children's Rehabilitation Center at Leesburg, Va.

Senator MONDALE. What would be the figure involved for the center?

Mr. FUNK. The center in 1972 would be either \$270,000 or \$220,000.

Senator MONDALE. Your audit shows \$270,000 here.

Mr. FUNK. The chapter development activities were the responsibility in 1972 as they are in 1973, of Don L. Organ. The Government liaison activities in 1972 were the responsibility of Melba Gandy. The Children's Center activities are an executive office responsibility, because there we are involved in the financial support; we are not involved in the operation of the center.

Patient services for the headquarters office of the foundation involves information and referral. The foundation receives from persons with epilepsy and from the parents of children with epilepsy up to 100,000 letters a year, and our patient service unit endeavors to answer those within a target of 48 hours, with a variety of consumer pamphlets.

That activity in 1972 was, I believe, headed by Hugh Gage at the beginning of the year, and later in the year by Helen Morgan.

Senator MONDALE. Are these people doctors?

Mr. FUNK. Are they doctors? No, sir, they are not.

Senator MONDALE. A patient or someone troubled with epilepsy will write in with a problem?

Mr. FUNK. Yes.

Senator MONDALE. Do they profess to give medical advice?

Mr. FUNK. Oh no, sir; they do not. On medical matters they would refer the person to their own physician.

Senator MONDALE. What kind of service do they give to the patients?

Mr. FUNK. There is a wide variety of questions. Indeed the questions tend to fall into a pattern, and I think the best description of that was given a week ago at the Western Institute on Epilepsy in Denver, Colo., where Mrs. Ellen Grass, who has been answering such letters for many, many years, put together what one might call a composite.

The questions are these kinds of questions. They relate to: How can I get a job? They relate to questions on driver's licenses. There are questions on: Should I marry? There are questions on a wide variety of topics.

All of those topics have been studied, poured over at one time or another by our Professional Advisory Board, and the answers are incorporated in a series of consumer pamphlets.

Where there are special questions, not answered by the pamphlets or not answered by the stock paragraphs we have on file for use on the MTST machines; those are referred to the committee of the Professional Advisory Board which formulates a special answer for that purpose.

Senator MONDALE. I have a letter here which I gather is the fund-raising letter which goes out in your mail solicitation. There is a little part up here which usually has the penny attached. I understand it is a standard letter signed by A. B. Baker, M.D., chairman. Would that be a typical letter that goes out in your mail solicitation?

Mr. FUNK. Yes, it would. I think perhaps I should first explain that there are two main parts in our mail solicitation.

The solicitation of known donors, which are on a house list—and the letter you have in your hand does not go to them, because they have contributed to the foundation earlier; they are more familiar with our activities, and they receive a different kind of communication. That is one activity.

The other activity is to what might be termed "prospects" or "potential donors," and the intent here is not only to generate revenue but to replace names onto the house list of known donors, because over a period of time those names disappear because people move, or there has been some other change in their situation, and we lost contact with them.

Senator MONDALE. So you have one list that you call your house list which is, I gather, people who donate repeatedly?

Mr. FUNK. Yes.

Senator MONDALE. Then you have another list, or you work on another list to try to develop new donors, and when they give, they are transferred to the house list.

Mr. FUNK. That is correct.

Senator MONDALE. I guess we have found one with the new penny attached, and then a list of some stamps called "Light the Candle of Understanding."

Would that be a typical letter then that goes to the prospective list?

Mr. FUNK. Yes, and this is the one majorly used. Over the past 8 or 10 years I think we have tested—we have conducted over the last couple of years some 50 tests to improve upon the effectiveness of that letter. Thus far we have not done so.

Senator MONDALE. So this almost identical letter is sent out from year to year to these lists?

Mr. FUNK. Yes, it is.

Senator MONDALE. How much was spent in 1972, the last year that you had audited completely, on pennies? How much did you pay for the pennies?

Mr. FUNK. On pennies I would think the figure would be somewhere between \$100,000 and \$110,000.

Senator MONDALE. Can Mr. Smith tell us precisely?

Mr. SMITH. No, I do not know precisely. It would be, I would say, one-hundredth of the number of pieces mailed that way. I would agree with Mr. Funk in general that it sounds about the right order of magnitude.

Senator MONDALE. Did you bring any records with you that would help us to get a precise figure?

Mr. SMITH. No, sir, but I can get those records if you wish.

Mr. FUNK. I think, Mr. Chairman, that we could guess at it this way. Out of the total letters mailed when one deducts the letters to the house list, virtually all the remainder would have pennies.

Senator MONDALE. In 1972 how many letters were mailed to house list people? How many were mailed to the remaining list?

Mr. FUNK. I would think that the house list would be just under 6 million.

Mr. ENNIS. Yes.

Mr. FUNK. And if my memory serves me correctly, the total would be 17 million—16 million.

Senator MONDALE. You may have about 16 to 17 million letters?

Mr. ENNIS. Sixteen.

Senator MONDALE. How does that come out broken down between house list and nonhouse list?

Mr. FUNK. I believe that about 6 million of the total would be house list.

Mr. ENNIS. Yes.

Mr. FUNK. And the balance would be to potential donors.

Senator MONDALE. So between 10 and 11 million was sent out with pennies in them?

Mr. FUNK. Yes.

Senator MONDALE. Of course that is quite an expense, those pennies. Does this result in any criticism?

Mr. FUNK. Yes, but the penny letter is even after deduction for the cost of the penny about 18 percent more effective than without. We have sent the same letter with a printed penny, we have sent the letter with other tip-ons; it does not produce the same result.

Senator MONDALE. How much more expensive is this letter when you send it out without a penny? What percentage of the total packet is involved in pennies?

Mr. FUNK. I would defer to our direct mail people, but, as I recall, our letters go into the mail at a cost of about \$68 to \$71 a thousand.

Senator MONDALE. Does that include the penny?

Mr. ENNIS. It does; yes.

Senator MONDALE. This is what goes out in the mail [indicating]: an envelope, this letter with the penny and the stamps; is that correct?

Mr. FUNK. Right.

Senator MONDALE. What does one packet cost you? How does it work out? Approximately how much for one packet?

Mr. FUNK. Six or seven cents.

Mr. SMITH. Seven cents.

Mr. FUNK. About 7 cents.

Senator MONDALE. So that about one-sixth or one-seventh of the cost of the letter is involved in this penny?

Mr. FUNK. That would be correct.

Senator MONDALE. If I were to respond to this letter and give a dollar, how much would go to the national office and how much to my local chapter?

Mr. FUNK. If you were to respond to that letter, the entire dollar would go to the national office.

Senator MONDALE. No money is sent to the local chapter?

Mr. FUNK. Not directly as a result of mail. From time to time money is advanced to local chapters to help them develop in their early phases, but by and large the fundraising activities carried on by the national office, the revenues derived therefrom, are retained by the national office.

Senator MONDALE. So when I look at your account for 1972, analysis of functional operating expenditures, I should be able to tell exactly how my contribution was spent in that year; is that correct?

Mr. FUNK. That is correct.

Senator MONDALE. Looking at the statement, I see that out of \$3.2 million in total expenditures, \$1.3 million went for fundraising; is that correct?

Mr. FUNK. That sounds correct, Senator.

Senator MONDALE. So that is about 40 percent of the money going for fundraising cost?

Mr. FUNK. Out of the national office, that would be correct; about 39 percent.

Senator MONDALE. Now in previous years what kind of percentage did you have?

Mr. FUNK. Over the last 5 years the highest percentage was 53 percent, and that would be 1969. In 1970 it was 46; in 1971 it was 42; in 1972 it was 39. In 1973, although the figures are not yet audited, it would appear to be slightly below 39.

Mr. SMITH. Yes, sir.

Senator MONDALE. Our figures are slightly different.

For 1969 we show \$2.1 million in total income, fundraising costs of \$1.17 million for 57 percent.

In 1970 we show income of \$2.3 million, fundraising costs of \$1.1 million for 48 percent.

In 1971 we show \$2.7 million income, \$1.1 million in fundraising costs for 44 percent.

In 1972 we show \$3.2 million in income, \$1.2 million in costs, for 40 percent.

In 1973 we show \$3.5 million income, \$1.4 million in fundraising costs, for 42 percent.

In every case our figures are about 2 or 3 percent higher than yours. We took these off your own national annual report.

Mr. FUNK. They should therefore be the same.

Senator MONDALE. We are dealing with the same arithmetic.

Mr. FUNK. I am not sure that I followed that step by step, but the answer I am sure can be very quickly arrived at.

Senator MONDALE. We will submit our figures which, as I say, were taken from your own reports, to you, and you might submit for the record what accounts for the difference.

Do you consider these fundraising costs to be high?

Mr. FUNK. Yes, we do.

Senator MONDALE. Why does such a high percentage of your money go into fundraising costs?

Mr. FUNK. I do not know, Senator, that is a voluntary act. Percentage is the end result of what comes back.

Senator MONDALE. I understand.

Mr. FUNK. Our average gift from the general public currently I believe is \$3.13. Were that to go to \$6 that would automatically cut those costs in half.

Senator MONDALE. As I understand it, on the National Health Council standards this is the highest percentage of any charity affiliated with the National Health Council.

Mr. FUNK. I think that is correct, Senator.

Senator MONDALE. I am told the average is under 25 percent. Would you explain why it costs more money, why it is higher percentage-wise to raise money?

Mr. FUNK. Yes. In my judgment that would relate to the stigma which has long been associated with epilepsy. There are many people who are invited to join our board—nationally or locally—who do so with a considerable amount of trepidation, for fear that they will be identified as having epilepsy.

Discrimination and stigma are realities for the person with epilepsy. Our movement therefore is handicapped in attracting volunteers to do fundraising and to find leading members of the community to encourage in our activities.

I think there are direct correlations between the unemployment figures for people with epilepsy and the difficulty that the organization working in their behalf have in raising money.

Senator MONDALE. So you think it is an unpopular and mysterious disease which stigmatizes those who have it and those who give toward its alleviation.

Mr. FUNK. And of those who endeavor to work in the field.

Senator MONDALE. According to your statement, operating expenses, the foundation spent \$726,000 on salaries in 1972. Of that you list a little over \$52,000 of your salaries and fundraising.

Mr. FUNK. Correct.

Senator MONDALE. Was any of your salary included in that figure?

Mr. FUNK. I would have to assume that it was.

Senator MONDALE. Can your accountant tell us?

Mr. SMITH. I do not know, sir.

Senator MONDALE. You do not know.

Mr. SMITH. No sir.

Senator MONDALE. Explain that. Did you prepare that audit?

Mr. SMITH. I was not there at that time.

Mr. FUNK. You are talking about 1972, sir?

Senator MONDALE. Yes.

Mr. SMITH. For 1972 I do not know. I have never seen the spread percentages on salaries for 1972.

Senator MONDALE. Have you prepared the 1973 audit?

Mr. SMITH. Yes sir.

Senator MONDALE. Did you include any of Mr. Funk's income in fundraising?

Mr. SMITH. I do not recall precisely. I believe so, but I will have to check on that. They were not prepared by me.

Senator MONDALE. Do you have any record with you?

Mr. SMITH. I do not have the sheet with me; no, sir. I do not know.

Senator MONDALE. Mr. Funk, you do not know whether it was?

Mr. FUNK. I would be certain there is some percentage of salary.

Senator MONDALE. But you do not know from your own personal knowledge?

Mr. FUNK. No; I do not. The figure developed there, which is one that we developed monthly, is a responsibility of Mr. Smith's superior, General Shannon, and he bases it on projects according to what our estimates of time was going to be.

Senator MONDALE. I think you know what I am trying to arrive at. One of the key questions that the National Health Council deals with, among others, is whether general overhead is being fairly allocated to fundraising so that the fundraising percentages are accurate.

There is a tendency, perhaps an understandable one, to try to downplay fundraising costs and allocate those costs to other purposes. That is why I am asking these questions about the allocations.

Mr. FUNK. I might say this, if I might, Senator, that the foundation does a forward plan for the coming year's activities. It is about this thick [indicating]. One portion of that is a detailed estimate, employee by employee, as to the amount of time required to carry out each project, and those totals are exchanged between departments, so that department heads can make time available.

This would be the basic document for recording time, and is the one preliminary referred to.

The only changes then would be the differences between the plan and reality, and there are indeed differences between plans and reality.

Senator MONDALE. You must have some basic document that shows how these costs are allocated, do you not?

Mr. FUNK. How our costs are allocated?

Senator MONDALE. Yes.

Mr. FUNK. The basic document would be a book published by the National Health Council called "Standards."

Senator MONDALE. I am talking about in your own operation when you take your total expenditures and allocate them for various purposes, including fundraising. You must have some document.

Mr. FUNK. Oh yes.

Senator MONDALE. What do you call that document?

Mr. FUNK. That is the official budget for the year.

Senator MONDALE. It shows these costs, how overhead is allocated?

Mr. FUNK. This would be the forward plan for each year [indicating].

Senator MONDALE. No. I mean after the year is completed, and you allocate costs among various categories, among fundraising you must have some document that shows that.

Mr. FUNK. Yes, we do, sir.

Senator MONDALE. What do you call that?

Mr. FUNK. The operating budget [indicating]. This is a set.

Senator MONDALE. That is 1974.

Mr. FUNK. That is 1974.

Senator MONDALE. Now, in 1972 do you have a document that shows how money was allocated and broken down?

Mr. FUNK. Yes, we do.

Senator MONDALE. Do you have that with you?

Mr. FUNK. I do not have that with me.

Senator MONDALE. What is that document called?

Mr. FUNK. That would be the 1972 budget.

Senator MONDALE. I think we are talking about two different things. Your budget is how you intend to spend your money.

Mr. FUNK. Right.

Senator MONDALE. At the end of the year you have to make a statement of how the moneys were spent and how it was allocated among categories. What is that document called?

Mr. FUNK. That would be the accounting records themselves, and they would follow very closely the budget, except where there were new activities.

Senator MONDALE. What I am getting at is you have an analysis of functional operating expenditures. Someone had to make your total expenditures and allocate some to research, some to community service, some to management, some to fundraising, and so on. Do you have a working sheet that will show us how that money was distributed?

Mr. FUNK. The books themselves will, Senator; and the detail.

Mr. KATZ. Mr. Funk, we have looked over the 1972 and 1973 books and schedules, accounts, which I think you brought with you today. There were a lot of categories that did not indicate by definition which costs those particular categories would be listed under when you finally made up your audit. Remember we talked about it?

Mr. SMITH. Yes.

Mr. KATZ. Membership campaign, the various travel expenditures—and there were salaries, things like that.

In looking at these schedules, ledgers, and journals, there is no way to tell whether those salaries and membership campaigns, or anything like that, would go under fundraising, research, or anything like that. Is that not true?

Mr. SMITH. Partially. The direct costs that we could identify at the time the expenditures was made was allocated directly on those sheets to a particular function. In the case of salaries, which is not a direct cost, that is correct.

If you are talking about a schedule which would list employees and how their time percentages would be spread, I do have such a schedule for 1973. I do not have it with me. I can get it—not for 1972.

Senator MONDALE. Is there such a document for 1972 in the files?

Mr. SMITH. I have not seen one.

Senator MONDALE. There would have to be.

Mr. SMITH. There would have to be; yes.

Mr. FUNK. There would have had to have been, however I doubt if it was retained past the point where the spread was certified by the auditors.

Senator MONDALE. Why should that be?

Mr. FUNK. Sheer filing space I would think. Once the auditor has certified the spread, there would be very little point in keeping the more voluminous documentation.

Senator MONDALE. Does Price Waterhouse keep it?

Mr. FUNK. Yes, sir.

Senator MONDALE. Do you know if they have it?

Mr. FUNK. If they have retained one that explains how we arrived at this [indicating], I would imagine so.

Senator MONDALE. Would you find this out and submit it for the record, if they have.

Mr. FUNK. I would be very happy to.

Senator MONDALE. And would you submit the 1973 allocation sheet for us?

Mr. SMITH. Yes.

Senator MONDALE. And if you have a documentation for previous years of that kind, also submit that to us.

Mr. SMITH. Very well Senator.

Senator MONDALE. We have a form from IRS. In 1972 it lists your compensation as \$41,983, Mr. Funk; is that correct?

Mr. FUNK. For 1972? I think it was \$41,500.

Senator MONDALE. I have \$41,983.

Mr. FUNK. That is probably correct.

Senator MONDALE. Discreetly beneath a Congressman's salary.

In 1971 and under that same document you list \$50,000 as your salary.

Mr. FUNK. \$50,000? That would be incorrect. My compensation is covered by a contract which I believe the committee has a copy of in its possession. As far as I know this overstates my compensation.

Senator MONDALE. According to your employment contract, your salary was \$42,000 a year, plus a \$12,000 bonus.

Mr. FUNK. Bonus, I am not sure is an accurate description.

Senator MONDALE. What do you call it?

Mr. FUNK. There was a contract assigning compensation in return for the restrictions detailed in the contract.

Senator MONDALE. The foundation shows paid to you \$12,000 on the signing of this agreement. Was that paid?

Mr. FUNK. Yes.

Senator MONDALE. Is that an annual payment?

Mr. FUNK. No. At the beginning of the contract period.

Senator MONDALE. So that your salary is limited to roughly \$41,000 a year, and you received no other compensation from the foundation except the \$12,000 paid to you in the year that you signed the employment contract?

Mr. FUNK. That is accurate.

Senator MONDALE. In May 1972 you entered into a second employment contract that took effect next December. This provided for a salary of \$44,500 a year, during 1973, and 1974, and also for another \$12,000 for signing the contract. Is that accurate?

Mr. FUNK. That is accurate.

Senator MONDALE. So what do you do? You enter into a 2-year contract?

Mr. FUNK. Yes.

Senator MONDALE. And each time you sign a contract in addition to your annual compensation you get \$12,000 for performing what?

Mr. FUNK. The contract, as you will note, places a wide variety of restrictions on my activities should I leave the foundation. It provides that there are certain kinds of organizations that I may not work for, and that there are certain activities I may not engage in.

Senator MONDALE. It is sort of a contract not to compete?

Mr. FUNK. Essentially, yes.

Senator MONDALE. These 2-year contracts give you \$12,000 each time for agreeing to refrain from such?

Mr. FUNK. Correct.

Senator MONDALE. Do you consider that income?

Mr. FUNK. Yes, I do.

Senator MONDALE. When did you receive the \$12,000 for the 1973-74 contract?

Mr. FUNK. I would think in the fall of 1972.

Senator MONDALE. Why did you not include that in your statement of income to the IRS?

Mr. FUNK. In 1972 it should be. I would think that those statements are inaccurate in that respect. I have not previously seen them, nor did I sign them.

Senator MONDALE. Let us see. There was a contract entered into in 1970 which you signed in December, which paid you compensation of \$41,000, I believe plus \$12,000 in your contract.

Then you entered into a very similar agreement on May 11, 1972, with the foundation in which your compensation is listed as \$44,500, and added to that was \$12,000 for the same agreement, in effect not to compete.

Have you entered into a previous agreement like this?

Mr. FUNK. No.

Senator MONDALE. There have been two contracts in which you received the \$12,000 for not competing?

Mr. FUNK. That is correct.

Senator MONDALE. I have here a report filed with the State of Illinois, signed by you, on behalf of the Epilepsy Foundation, which lists your compensation as \$41,983. Is that a fair presentation of your income in the light of these \$12,000 agreements?

Mr. FUNK. If it asks for salary, then that would be I think how we would answer. If it asks for total compensation, it would not be accurate.

Senator MONDALE. It says list of employees earnings in excess of \$20,000 per annum, schedule E, so you think that is an accurate representation of your earnings?

Mr. FUNK. I would like to look at that document, sir, and the description.

I think our interpretation would have been they were asking for information on salary, and that we answered it in that manner.

[Document was handed to witness.]

Senator MONDALE. How did you receive this \$12,000? Was it spread, or did you get a lump sum?

Mr. FUNK. Lump sum.

Senator MONDALE. I assume you listed that as income in your income tax?

Mr. FUNK. I did indeed.

Senator MONDALE. If you sign another contract in 1974, with the foundation, to extend your services, would you contemplate you would sign another contract for agreeing not to compete?

Mr. FUNK. I think it would depend upon my situation and the foundation's situation at the time.

Senator MONDALE. For the past 3 years the foundation has, I understand, been leasing to you an auto at a cost of about \$2,600 per year. Is this car for your use, Mr. Funk?

Mr. FUNK. That car is for foundation use, Senator. I am probably the one making the greatest use of it. I also use it to some extent for personal purposes, for which I reimburse the foundation.

Senator MONDALE. What kind of car is it?

Mr. FUNK. It is an American Motors sedan.

Senator MONDALE. I have 1973 American AMX.

Mr. FUNK. That would be correct.

Senator MONDALE. Do you use it to drive to and from work?

Mr. FUNK. On occasion.

Senator MONDALE. How much do you pay the charity for your personal use of this car?

Mr. FUNK. I do not recall the figure, but I have supplied it to the subcommittee earlier.

Senator MONDALE. Would it be fair to say this is a sports car?

Mr. FUNK. I would not so describe it. Our last car was a Buick which most of us had trouble getting parked in the space available.

Senator MONDALE. In 1970 you had a Buick Riviera.

Mr. FUNK. Our feeling was the model was a little easier to get into garages and parking space.

Senator MONDALE. Do you consider that any part of the value of that car should be considered compensation to you?

Mr. FUNK. I do not.

Senator MONDALE. Do you have a second car at home?

Mr. FUNK. I do not.

Senator MONDALE. So you must use it for personal use?

Mr. FUNK. My answer is that I do use it for personal use, and that I reimburse the foundation for that use.

Senator MONDALE. At this time I ask unanimous consent that copies of Mr. Funk's salary agreements with the Epilepsy Foundation of America (EFA) and a copy of the car leasing contract be printed in the record.

[The information referred to follows:]

EMPLOYMENT AGREEMENT**BEST COPY AVAILABLE**

AGREEMENT made this 11th day of December, 1970, between PAUL E. FUNK presently of Port Chester, New York (hereinafter referred to as "Employee") and EPILEPSY FOUNDATION OF AMERICA, a Delaware non-profit corporation having a principal place of business in the District of Columbia, (hereinafter referred to as "Foundation").

WHEREAS, FOUNDATION after discussion by the Executive Committee and the Board of Directors of said FOUNDATION and pursuant to a resolution of the Executive Committee and ratification thereof by the Board of Directors, wishes to obtain the services of EMPLOYEE as Executive Vice President and Chief Executive Officer of said FOUNDATION and EMPLOYEE is desirous of being employed by said FOUNDATION in said capacity. It is agreed that:

1. EMPLOYMENT. FOUNDATION hereby employs EMPLOYEE and EMPLOYEE hereby accepts employment upon all of the terms and conditions hereinafter set forth.

2. TERM. The term of this Agreement shall be deemed to have begun on December 1, 1970 the day immediately following the ratification by the Board of Directors of said FOUNDATION and shall terminate on November 30, 1972, with the right of the parties to renew this Agreement for an additional period of time and on terms agreed to by both, but such renewal shall be signified by written agreement between the parties not less than sixty (60) days before expiration hereof.

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3. COMPENSATION. The EMPLOYEE shall be entitled to the following compensation during the term of this Agreement for the signing of this Agreement and for services rendered in accordance herewith:

(a) The FOUNDATION shall pay to the EMPLOYEE the sum of Twelve Thousand Dollars (\$12,000.00) upon the signing of this Agreement.

(b) During the years 1971 and 1972, the FOUNDATION shall pay to the EMPLOYEE the sum of Forty-Two Thousand Dollars (\$42,000.00), during each year, in installments as is customary for salary payments to FOUNDATION's executive personnel. All of the above compensation is subject to necessary deductions, including but not limited to, Federal withholding tax, Social Security, Insurance, State and Local taxes, and any other normal payroll deductions. The EMPLOYEE shall be entitled fringe benefits, including but not limited to, hospitalization or pension plan as other employees of the FOUNDATION presently enjoy or may hereafter enjoy during the term of this Agreement.

4. DUTIES. EMPLOYEE is engaged as Executive Vice President of the FOUNDATION to assist the President and direct FOUNDATION's operations, personnel, public relations and all other aspects of the necessary business of the FOUNDATION. The precise services of EMPLOYEE may be extended or curtailed from time to time at the direction of the President and of the Board of Directors of the FOUNDATION. EMPLOYEE's service

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as Executive Vice President of FOUNDATION shall include his services under this contract and any other services in subsidiary corporations or chapters.

5. EXTENT OF SERVICES. EMPLOYEE shall devote his entire time, attention and energies to the business of the FOUNDATION and shall assume and perform such further reasonable responsibilities and duties as may be assigned to him from time to time by FOUNDATION, its President and its Board of Directors. EMPLOYEE shall not, during the term of this Agreement, be engaged in any other business activities related to or for other voluntary health organizations, whether or not such business activity is pursued for gain, profit, or other pecuniary advantage; but this shall not be construed as preventing EMPLOYEE from investing his assets as he sees fit.

6. WORKING FACILITIES. EMPLOYEE shall be furnished with a private office, stenographic help, and such other facilities and services which are suitable to his position and adequate for the performance of his duties.

7. EMPLOYEE COVENANTS

(a) Trade Secrets. All donor and/or mailing lists and other information concerning donors and annual income, and all inventions, formulas, methods, processes and technical information used in the business or operations or in the possession of the FOUNDATION, will be held in confidence by the EMPLOYEE and will not be disclosed, made

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public or made use of by or through him, directly or indirectly, while EMPLOYEE is employed by the FOUNDATION or at any time thereafter.

(b) EMPLOYEE further agrees that he will not at any time whether prior to or after the termination of this Agreement, proselytize or pirate, directly or indirectly, on his own behalf or on behalf of any other person, firm, partnership, or corporation, any personnel of FOUNDATION or its chapters. EMPLOYEE further agrees that he will not, at any time, whether prior to or after the termination of this Agreement, directly or indirectly, alone or together with any person, persons, firm, partnership, or corporation hire or engage any such personnel until one year after they shall have terminated their employment, association or affiliation with FOUNDATION.

(c) Non-Competition. EMPLOYEE will not for three years from the termination of his employment with the FOUNDATION, directly or indirectly, alone or with others whether as a partner, officer, director, employee, agent, consultant, shareholder or otherwise, own, manage, operate, participate in, engage in or carry on any work similar to or relating to the business of the FOUNDATION as it is now engaged or may be engaged at the time of termination of his employment hereunder, including but not limited to fund raising, obtaining of Government grants, chapter development programs and public relations.

8. FOUNDATION COVENANTS.**BEST COPY AVAILABLE**

(a) FOUNDATION agrees that it will provide three (3) weeks paid vacation annually, said vacation to be a total of twenty-one (21) days and include Saturdays, Sundays and legal holidays.

(b) FOUNDATION agrees to pay reasonable expenses of moving EMPLOYEE's personal effects from New Caanen, Connecticut to the metropolitan Washington, D. C. area, if such move actually takes place with a maximum allowance for all costs incident to said moving in the amount of Fifteen Hundred Dollars (\$1,500.00).

9. DISABILITY OF EMPLOYEE. If EMPLOYEE shall become unable to perform his duties hereunder because of any physical or mental condition, he shall nevertheless be entitled to his regular compensation until the total period of disability shall exceed an aggregate of two (2) months in any year, and as to any subsequent periods of disability in such year, EMPLOYEE shall not be entitled to compensation. If the total period of disability in any year shall exceed an aggregate of four (4) months, either EMPLOYEE or FOUNDATION may give notice of termination of this contract. Such notice shall be effective thirty (30) days after given.

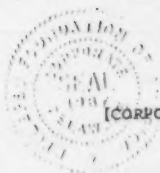
10. DEATH OF EMPLOYEE. In the event of the death of EMPLOYEE during the term of this Agreement, this Agreement shall terminate immediately.

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11. BINDING EFFECT. The rights and obligations of FOUNDATION under this Agreement shall inure to the benefit of and be binding upon the successors and assigns of FOUNDATION. Rights acquired hereunder by FOUNDATION's parent corporation and affiliated corporations may be exercised in its or their own name.

IN WITNESS WHEREOF, the parties hereto have executed this Agreement on the date first hereinabove written, at Washington, D. C.



[CORPORATE SEAL]

ATTEST:

John G. Warden
SECRETARY

EPILEPSY FOUNDATION OF
AMERICA

By:

A. B. Baker
A. B. BAKER, PRESIDENT

Paul E. Funk
PAUL E. FUNK, EMPLOYEE

EMPLOYMENT AGREEMENT

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AGREEMENT made this 11th day of May, 1972, between PAUL E. FUNK of Washington, D. C., and presently Executive Vice President of EPILEPSY FOUNDATION OF AMERICA (hereinafter referred to as "Employee") and EPILEPSY FOUNDATION OF AMERICA, a Delaware non-profit corporation having its principal place of business at 1828 L Street, N. W. in the District of Columbia (hereinafter referred to as "Foundation").

WHEREAS, EMPLOYEE and FOUNDATION after discussion by the Executive Committee and the Board of Directors of said FOUNDATION and pursuant to a resolution of the Executive Committee on April 12, 1972, wishes to retain the services of EMPLOYEE as Executive Vice President and Chief Executive Officer of said FOUNDATION, said EMPLOYEE having originally been employed under an Employment Agreement dated December 11, 1970. It is agreed that:

1. EMPLOYMENT. FOUNDATION hereby exercises the option contained in Paragraph 2 of the Agreement dated December 11, 1970, by offering to EMPLOYEE an additional two-year contract beginning on December 1, 1972, and said EMPLOYEE hereby accepts employment with the FOUNDATION upon all of the terms and conditions hereinafter set forth.

2. TERM. The term of this Agreement shall begin on December 1, 1972. This term being an extension of the Agreement deemed to have begun on December 11, 1970. The parties hereto shall have the right to renew this Agreement for an additional period of time and on terms agreed

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- 2 -

to by both, but such renewal shall be signified by written agreement by the parties not less than sixty (60) days before the expiration hereof said expiration date being November 30, 1974.

3. COMPENSATION. The EMPLOYEE shall be entitled to the following compensation during the term of this Agreement for the signing of this Agreement and for services rendered in accordance herewith:

(a) The FOUNDATION shall pay to the EMPLOYEE the sum of Twelve Thousand Dollars (\$12,000.00) upon the execution of this Agreement notwithstanding the fact that the said execution may occur prior to the expiration of the original agreement on November 30, 1972.

(b) During the years 1973 and 1974, the FOUNDATION shall pay to the EMPLOYEE the sum of Forty-four Thousand Five Hundred Dollars (\$44,500.00), during each year, in installments as is customary for salary payments to FOUNDATION's executive personnel. All of the above compensation is subject to necessary deductions, including but not limited to, Federal withholding tax, Social Security, Insurance, Medical Insurance, State and Local taxes, and any other normal payroll deductions. The EMPLOYEE shall be entitled to fringe benefits, including but not limited to, hospitalization or pension plan as other employees of the FOUNDATION presently enjoy or may hereafter enjoy during the term of this Agreement.

4. DUTIES. EMPLOYEE is engaged as Executive

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Vice President of the FOUNDATION to assist the President and direct FOUNDATION's operations, personnel, public relations and all other aspects of the necessary business of the FOUNDATION. The precise services of EMPLOYEE may be extended or curtailed from time to time at the direction of the President and of the Board of Directors of the FOUNDATION. EMPLOYEE's service as Executive Vice President of FOUNDATION shall include his services under this contract and any other services in subsidiary corporations or chapters.

3. EXTENT OF SERVICES. EMPLOYEE shall devote his entire time, attention and energies to the business of the FOUNDATION and shall assume and perform such further reasonable responsibilities and duties as may be assigned to him from time to time by said FOUNDATION, its President and/or its Board of Directors. EMPLOYEE shall not, during the term of this Agreement, be engaged in any other business activities related to or for other voluntary health organizations or organizations engaged in raising funds from the public, whether or not such business activity is pursued for gain, profit, or other pecuniary advantage; but this paragraph shall not be construed as preventing EMPLOYEE from investing his assets as he sees fit. Notwithstanding the foregoing, the FOUNDATION recognizes that EMPLOYEE may wish to devote some part of his time to his former profession in the Advertising and Public Relations business and the FOUNDATION specifically agrees that EMPLOYEE shall be allowed to devote a reasonable amount of time to maintaining his status in said professions and that any such work shall not conflict with his duties for the

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FOUNDATION and will be in no way engaged in for any other voluntary health organization or organizations engaged in raising funds from the public. The amount of time to be devoted by such said EMPLOYEE to his other professional activities shall be a matter of reasonableness and determined by the EMPLOYEE and the President of said FOUNDATION.

6. WORKING FACILITIES. EMPLOYEE shall be furnished with a private office, stenographic help, and such other facilities and services which are suitable to his position and adequate for the performance of his duties.

7. EMPLOYEE COVENANTS

(a) Trade Secrets. All donor and/or mailing lists and other information concerning donors and annual income, and all inventions, formulas, methods, processes and technical information used in the business or operations or in the possession of the FOUNDATION, will be held in confidence by the EMPLOYEE and will not be disclosed, made public or made use of by or through him, directly or indirectly, while EMPLOYEE is employed by the FOUNDATION or at any time thereafter.

(b) EMPLOYEE further agrees that he will not at any time whether prior to or after the termination of this Agreement, proselytize or pirate, directly or indirectly, on his own behalf or on behalf of any other person, firm, partnership, or corporation, any personnel of FOUNDATION or its chapters. EMPLOYEE further agrees that he will not, at

any time, whether prior to or after the termination of this Agreement, directly or indirectly, alone or together with any person, persons, firm, partnership, or corporation hire or engage any such personnel until one year after they shall have terminated their employment, association or affiliation with FOUNDATION.

(c) Non-Competition. EMPLOYEE will not for three years from the termination of his employment with the FOUNDATION, directly or indirectly, alone or with others whether as a partner, officer, director, employee, agent, consultant, shareholder or otherwise, own, manage, operate, participate in, engage in or carry on any work relating to the raising of funds from the public for any purpose whatsoever, including but not limited to fundraising, obtaining of Government grants, chapter development programs and public relations for such organizations.

(d) Notwithstanding the above paragraph, it is specifically understood and agreed by the parties hereto that EMPLOYEE shall have the right upon termination of his services for FOUNDATION to become employed by a recognized trade association that raises its money from companies or organizations within that trade association but not from the general public.

8. FOUNDATION COVENANTS

(a) FOUNDATION agrees that it will provide three (3) weeks paid vacation annually, said vacation to be a total of twenty-one (21) days and include Saturdays,

9. DISABILITY OF EMPLOYEE. If EMPLOYEE shall become unable to perform his duties hereunder because of any physical or mental condition, he shall nevertheless be entitled to his regular compensation until the total period of disability shall exceed an aggregate of two (2) months in any year, and as to any subsequent periods of disability in such year, EMPLOYEE shall not be entitled to compensation. If the total period of disability in any year shall exceed an aggregate of four (4) months, either EMPLOYEE or FOUNDATION may give notice of termination of this contract. Such notice shall be effective thirty (30) days after given.

10. DEATH OF EMPLOYEE. In the event of the death of EMPLOYEE during the term of this Agreement, this Agreement shall terminate immediately.

11. BINDING EFFECT. The rights and obligations of FOUNDATION under this Agreement shall inure to the benefit of and be binding upon the successors and assigns of FOUNDATION. Rights acquired hereunder by FOUNDATION's parent corporation and affiliated corporations may be exercised in its or their own name.

IN WITNESS WHEREOF, the parties hereto have executed this Agreement on the date first hereinabove written at Washington, D. C.

[CORPORATE SEAL]

EPILEPSY FOUNDATION OF
AMERICA

ATTEST:

W. S. Gardner

SECRETARY

By: *AB Baker*

BAKER, PRESIDENT
Paul E. Smith

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MOTOR VEHICLE LEASING AGREEMENT

Agreement made this 24th day of April, 1973, by and between
 EXECUTIVE AUTO LEASING, of Washington, D.C., Inc. having its principal place of business at 10330 Southard Drive, Beltsville, Md.
 hereinafter called Lessor, and Epilepsy Foundation of America
 of 1826 L Street N. W., Washington, D. C. hereinafter called Lessee.

1. Lessor hereby leases to Lessee for the period of 24 months and 6 days from the date of delivery, the motor vehicle and equipment described as follows:

1973 American AMX

Serial Number A3C798P259608

2. Lessor is depositing with Lessor the sum of \$ Transferred as a deposit to remain on Lessor's books during the term of this agreement, and which is to be refunded to Lessee on the expiration date of this agreement less any amounts then owing by Lessee to the Lessor.

3. In addition to said deposit, Lessee agrees to pay to Lessor the sum of \$ 3203.02 for rent of said motor vehicle, payable in monthly installments of \$ 215.00 each payable in advance, on the first day of each month. All payments are to be made at the office of the Lessor, 10330 Southard Drive, Beltsville, Maryland, or at such other place which Lessor may designate. Lessee agrees to pay 1/12 of the monthly payment per month as a service charge if payment is not received by the 10th of the month. 6 days at \$43.02

4. In addition to the foregoing, Lessee agrees to pay Lessor, a mileage charge of 30 per mile for each mile over 25,000 miles that the above described motor vehicle is driven during each 12 month period of this lease. Lessor also agrees to pay sales tax on the monthly payment and/or personal property tax in states where applicable.

5. Lessee agrees to return said vehicle to the Lessor's nearest office after each 6,000 miles said vehicle has been driven or upon expiration of each 90 days under the terms hereof whichever transpires sooner and to leave said motor vehicle at such times at said office for such reasonable periods as may be required to permit Lessor to properly service and maintain said motor vehicle in good working condition. In lieu thereof, Lessee may take the said vehicle after each 6,000 miles said vehicle has been driven or upon expiration of each 90 days under the terms hereof whichever transpires sooner to an authorized dealership handling this make vehicle for proper service and maintenance, provided further, however, that Lessee will make available to Lessor on demand billings or other documented proof sufficient to establish the fact of such service.

6. In compliance with paragraph 5 above, lessor shall at all times maintain said motor vehicle in proper working condition, and to that end lessor shall furnish all repairs, labor, parts, tires, lubrication, oil changing, anti-freeze and servicing required to maintain said motor vehicle in good condition, all such costs thereof to be borne by lessor, provided further, that in any event all repairs necessitated by negligence, misuse, abusive use of the vehicle shall be borne by Lessee.

7. If Lessor agrees to pay for repairs and in the event that any repair bill or charge for any maintenance has been incurred by Lessee at a garage or service station other than the garage designated for said maintenance by Lessor, Lessor shall reimburse Lessee for the amount of such bill or charge upon request of Lessee accompanied by receipted bills; provided however, that in the event such bill or charge shall exceed \$15.00 in amount, the consent of the Lessor shall be first obtained by the Lessee before such bill or charge is incurred by Lessee and provided further, that Lessee is at the time of such event in full compliance with the provisions of paragraph 5 above.

8. The lessor agrees to pay the State title tax, and to furnish current State license plates for said motor vehicle, which plates Lessee agrees to keep on said vehicle at all times. However, in the event Lessee moves from State where said leased automobile was originally titled, the expense of re-registering said vehicle in new State will be borne by the Lessee within the time required by said State.

9. Lessee shall furnish at his own expense all gasoline required to operate said motor vehicle during the continuance of this lease. Lessee shall pay for all storage, washing and cleaning of said motor vehicle, and shall garage said motor vehicle in a suitable place to protect the same.

10. Lessee shall cause said motor vehicle to be insured against loss by fire, theft and collision. The collision insurance shall be of the type known as \$100.00 deductible collision insurance, and if said motor vehicle becomes damaged in a collision in an amount less than

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\$100.00, the Lessee agrees to pay the cost of such damage, in the event of a collision involving an insurance claim, the Lessee agrees to pay the first \$100.00 as provided for in the policy. The cost of placing and maintaining said insurance shall be borne by the Lessee.

11. Lessee shall keep said motor vehicle insured against liability for personal injuries caused by said motor vehicle or its operation to the extent of \$100,000.00 per accident, subject to the limit of \$100,000.00 per person. Lessee shall also cause said motor vehicle to be insured against liability for damage to property caused by the operation of said motor vehicle, in the sum of \$25,000.00 per accident. In the case of the liability and property damage insurance, the Lessee agrees to have Lessor also named as an insured. The cost of placing and maintaining said insurance shall be borne by the Lessee. It is further understood and agreed that the foregoing insurance coverage is based upon current premium costs, and it is also agreed that any increase in rate of premiums for the aforesaid insurance during the term of the lease shall be borne by the Lessee.

12. Lessee shall use and operate said motor vehicle in compliance with all city, state and federal laws, ordinances, and regulations, and in the event of the violation of any law, regulation or ordinance of any constituted public authority, the Lessee shall hold Lessor harmless for any fines or penalties for such violation, and shall reimburse the Lessor for any loss sustained by Lessor by reason of such violation. In addition to and notwithstanding its rights to such reimbursement, the Lessor may in the event of such violation, at its option, cancel this contract.

13. It is expressly understood that this is a contract of leasing only and that the Lessee by these presents acquired no ownership, title or property rights or interest in or to the motor vehicle described in this agreement.

14. Lessor shall not be held responsible for damages, and its non-performance of this contract is excused, for delay or failure to perform hereunder when such delay or failure is due to accidents, fires, strikes, labor troubles, acts of God, war, acts of public authorities, delays or defaults caused by public carriers, the elements, or any other causes not in control of Lessor.

15. Lessee shall have the right to terminate this lease, without notice to the Lessee, if Lessee shall have filed a voluntary petition in bankruptcy, shall have made an assignment for the benefit of creditors or if an involuntary petition in bankruptcy shall be filed against Lessee, or if a receiver shall have been appointed for Lessee's assets, or if Lessee shall have permitted or suffered any distress, attachment, levy or execution to be made or levied against any or all of the property of Lessee, or if Lessee shall misuse said motor vehicle and such misuse causes abnormal wear to said motor vehicle. If Lessor shall elect to terminate this lease by reason of any of the events described in this paragraph, Lessee shall not be relieved of any liability for its failure to make any of the payments required under this agreement or for Lessee's failure or inability to perform any of the terms, covenants and conditions of this Agreement.

16. Time is of the essence of this Agreement and in the event Lessee shall be in default in any of the payments required of the Lessee to be made under this Agreement, or in the performance of any other covenant or condition required under this Agreement to be made or performed by Lessee, Lessor shall have the right, with or without notice, to terminate this Agreement and repossess the motor vehicle leased hereunder together with all accessories and equipment attached thereto, all without prejudice to such other remedies as Lessor may have for the collection of any sum or sums due or to become due Lessor from Lessee. If being entitled to repossess said motor vehicle, Lessor is unable to repossess the same, or Lessee otherwise defaults in any of the terms, conditions and covenants of this Agreement, Lessor shall have the right to employ an attorney to institute a replevin suit to repossess said motor vehicle or to collect any amount due Lessor, or to enforce any other breach by Lessee, for which Lessee hereby agrees to pay Lessor any costs, expenses and reasonable attorney's fees.

17. In the event of cancellation of this agreement by Lessee, prior to the term expressed herein or default by Lessee in performance of any of the covenants or conditions herein, Lessee shall pay as liquidated damages, to the Lessor the balance of the first year's rental plus 50% of the monthly rental charge for each additional unexpired month with a minimum of \$600.00 which represents the loss to the Lessor, directly caused by the Lessee's cancellation of this lease.

18. Lessor and Lessee agree that this instrument constitutes the entire Agreement between the two parties, and shall be binding on the respective parties and their respective heirs, executors, administrators, legal representatives, successors and assigns, and that any amendments, alterations, or supplementary provisions that may be made subsequent to the date of this Agreement must be made in writing and duly executed by each of the parties hereto.

19. Any notice given under this Agreement by Lessor to Lessee may be given personally or by registered mail addressed to Lessee at Lessee's address as set out in this Agreement. Any notice given under this agreement by Lessee to Lessor shall be given by sending by registered mail to Lessor at its address as in this Agreement set out (or such other address as Lessor shall have last furnished Lessee in writing), or by serving same personally at the office of the Lessor. In the event Lessee and Lessor agree to continue this Agreement beyond its expiration date, the same terms and conditions will apply as specified in this Agreement.

20. The failure of either party hereto in any one or more instances to insist upon the performance of any of the terms, covenants or conditions of this lease, to exercise any right or privilege of this Agreement conferred or the waiver of any breach of any of the terms, covenants or conditions of this Agreement, shall not be construed as thereafter waiving any such terms, covenants, conditions, rights or privileges, but the same continue and remain in full force and effect the same as if no such forbearance or waiver had occurred.

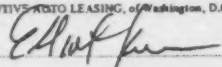
21. Lessor may assign this agreement along with collateral documents without prior consent of Lessee to financial institutions as security for any indebtedness of Lessor, and all right, title and interest of Lessor in the agreement shall inure to the benefit of the assignee and its successors and assigns. The Lessee may assign use of any unit after receiving written approval from Lessor.

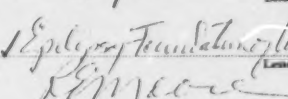
22. In the construction of this agreement the singular of any term shall include the plural and the plural of any term shall include the singular. Each gender shall include each of the other genders.

23. Upon the expiration, or sooner termination of this lease, the Lessee shall return and deliver said motor vehicle(s) to the Lessor at its place of business at 10330 Southard Drive, Beltsville, Maryland, in good order, condition and repair, reasonable wear and tear excepted. Any damage to said motor vehicle(s) shall be paid for by the Lessee to the Lessor. Tires shall have no more than 80% wear.

24. This Agreement has been executed in triplicate, each of the three copies being deemed to be an original. IN WITNESS WHEREOF the parties have hereunto caused these presents to be executed the day and year first above written.

EXECUTIVE AUTO LEASING, of Washington, D.C., Inc.

By:  Lessor

By:  Lessee

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Record Copy - Exec. Auto.

MOTOR VEHICLE LEASING AGREEMENT

Agreement made this 17th day of February, 1971, by and between
 EXECUTIVE AUTO LEASING, INC., having its principal place of business at 1025 Connecticut Avenue, N.W., Washington, D. C.,
 hereinafter called Lessor, and Epilepsy Foundation of America
 of 733 15th Street N.W. Washington, D.C., hereinafter called Lessee.

1. Lessor hereby leases to Lessee for the period of 24 months and 8 days from the date of delivery, the motor vehicle and equipment described as follows:

1971 Buick Riviera 2 Dr.
 Serial Number 494871 H 908172

2. Lessee is depositing with Lessor the sum of \$ 200.00 as a deposit to remain on Lessor's books during the term of this agreement, and which is to be refunded to Lessee on the expiration date of this agreement less any amounts then owing by Lessee to the Lessor.

3. In addition to said deposit, Lessee agrees to pay to Lessor the sum of \$ 5160.64 for rent of said motor vehicle; payable in monthly installments of \$ 212.50 each payable in advance, on the first day of each month. All payments are to be made at the office of the Lessor, 1025 Connecticut Avenue, N.W., Washington, D. C., or at such other place which Lessor may designate. Lessee agrees to pay 1% of the monthly payment per month as a service charge if payment is not received by the 10th of the month. 8 days at \$60.64.

4. In addition to the foregoing, Lessee agrees to pay Lessor, a mileage charge of 3c per mile for each mile over 25,000 miles that the above described motor vehicle is driven during each 12 month period of this lease. Lessee also agrees to pay sales tax on the monthly payment and/or personal property tax in states where applicable.

5. Lessee agrees to return said vehicle to the Lessor's nearest office after each 6,000 miles said vehicle has been driven or upon expiration of each 90 days under the terms hereof; whichever transpires sooner and to leave said motor vehicle at such time in good working condition. In lieu thereof, Lessee may be required to permit Lessor to properly service and maintain said motor vehicle in good working condition. In lieu thereof, Lessee may take the said vehicle after each 6,000 miles said vehicle has been driven or upon expiration of each 90 days under the terms hereof; whichever transpires sooner to an authorized dealership handling the make vehicle for proper service and maintenance, provided further, however, that Lessee will make available to Lessor on demand billings or other documented proof sufficient to establish the fact of such service.

6. In compliance with paragraph 5 above, LESSOR shall at all times maintain said motor vehicle in proper working condition, and to that end LESSOR shall furnish all repairs, labor, parts, tires, lubrication, oil changing, anti-freeze and servicing required to maintain said motor vehicle in good condition, all such costs thereof to be borne by LESSOR, provided further, that in any event all repairs necessitated by negligence, misuse, abusive use of the vehicle shall be borne by Lessee.

7. If Lessor agrees to pay for repairs and in the event that any repair bill or charge for any maintenance has been incurred by Lessee at a garage or service station other than the garage designated for said maintenance by Lessor, Lessor shall reimburse Lessee for the amount of such bill or charge upon request of Lessee accompanied by receipted bills; provided however, that in the event such bill or charge shall exceed \$15.00 in amount, the consent of the Lessor shall be first obtained by the Lessee before such bill or charge is incurred by Lessee and provided further, that Lessee is at the time of such event in full compliance with the provisions of paragraph 5 above.

8. The LESSOR agrees to pay the State title tax, and to furnish current State license plates for said motor vehicle, which plates Lessee agrees to keep on said vehicle at all times. However, in the event Lessee moves from State where said leased automobile was originally titled, the expense of re-registering said vehicle in new state will be borne by the Lessee within the time required by said State.

9. Lessee shall furnish at his own expense all gasoline required to operate said motor vehicle during the continuance of this lease. Lessee shall pay for all storage, washing and cleaning of said motor vehicle, and shall garage said motor vehicle in a suitable place to protect the same.

10. LESSEE shall cause said motor vehicle to be insured against loss by fire, theft and collision. The collision insurance shall be of the type known as "100-0-100 deductible collision insurance, and if said motor vehicle becomes damaged in a collision to an amount less than \$100.00, the Lessee agrees to pay the cost of such damage, in the event of a collision involving an

insurance claim, the Lessee agrees to pay the first \$100.00 as provided for in the policy. The cost of placing and maintaining said insurance shall be borne by the Lessee.

11. Lessee shall keep said motor vehicle insured against liability for personal injuries caused by said motor vehicle or its operation to the extent of \$ 500,000 per accident, subject to the limit of \$ 100,000 per person. Lessee shall also cause said motor vehicle to be insured against liability for damage to property caused by the operation of said motor vehicle to the sum of \$ 25,000 per accident. In the case of the liability and property damage insurance, the Lessee agrees to have Lessee also named as an insured. The cost of placing and maintaining said insurance shall be borne by the Lessee. It is further understood and agreed that the foregoing insurance coverage is based upon current premium costs, and it is also agreed that any increase in rate of premiums for the aforesaid insurance during the term of the lease shall be borne by the Lessee.

12. Lessee shall use and operate said motor vehicle in compliance with all city, state and federal laws, ordinances, and regulations, and in the event of the violation of any law, regulation or ordinance of any constituted public authority, the Lessee shall hold Lessor harmless for any fines or penalties for such violation, and shall reimburse the Lessor for any loss sustained by Lessor by reason of such violation. In addition to and notwithstanding its rights to such reimbursement, the Lessor may in the event of such violation, at its option, cancel this contract.

13. It is expressly understood that this is a contract of leasing only and that the Lessee by these presents acquired no ownership, title or property rights or interest in or to the motor vehicle described in this agreement.

14. Lessor shall not be held responsible for damages, and its non-performance of this contract is excused, for delay or failure to perform hereunder when such delay or failure is due to accidents, fires, strikes, labor troubles, acts of God, war, acts of public authorities, delays or defaults caused by public carriers, elements, or any other causes not in control of Lessor.

15. Lessor shall have the right to terminate this lease, without notice to the Lessee, if Lessee shall have filed a voluntary petition, in bankruptcy, shall have made an assignment for the benefit of creditors or if an involuntary petition in bankruptcy shall be filed against Lessee, or if a receiver shall have been appointed for Lessee's assets, or if Lessee shall have permitted or suffered any distress, attachment, levy or execution to be made or levied against any or all of the property of Lessee, or if Lessee shall misuse said motor vehicle and such misuse causes abnormal wear to said motor vehicle. If Lessor shall elect to terminate this lease by reason of any of the events described in this paragraph, Lessee shall not be relieved of any liability for its failure to make any of the payments required under this agreement or for Lessee's failure or inability to perform any of the terms, covenants and conditions of the Agreement.

16. Time is of the essence of this Agreement and in the event Lessee shall be in default in any of the payments required of the Lessee to be made under this Agreement, or in the performance of any other covenant or condition required under this Agreement to be made or performed by Lessee, Lessor shall have the right, with or without notice, to terminate this Agreement and repossess the motor vehicle leased hereunder together with all accessories and equipment attached thereto, all without prejudice to such other remedies as Lessor may have for the collection of any sum or sums due or to become due Lessee from Lessee. If being entitled to repossess said motor vehicle, Lessor is unable to repossess the same, or Lessee otherwise defaults in any of the terms, conditions and covenants of this Agreement, Lessor shall have the right to employ an attorney to institute a replevin suit to repossess said motor vehicle or to collect any amount due Lessor, or to enforce any other remedy by Lessee, for which Lessee hereby agrees to pay Lessor any costs, expenses and reasonable attorney's fees.

17. In the event of cancellation of this agreement by Lessee, prior to the term expressed herein or default by Lessee in performance of any of the covenants or conditions herein, Lessee shall pay as liquidated damages, to the Lessor the balance of the first year's rental plus 50% of the monthly rental charge for each additional unexpired month with a minimum of \$600.00 which represents the loss to the Lessor, directly caused by the Lessee's cancellation of this lease.

18. Lessor and Lessee agree that this instrument constitutes the entire Agreement between the two parties, and shall be binding on the respective parties and their respective heirs, executors, administrators, legal representatives, successors and assigns, and that any amendments, alterations, or supplementary provisions that may be made subsequent to the date of this Agreement must be made in writing and duly executed by each of the parties herein.

19. Any notice given under this Agreement by Lessor to Lessee may be given personally or by registered mail addressed to Lessee at Lessee's address as set out in this Agreement. Any notice given under this agreement by Lessee to Lessor shall be given by sending by registered mail to Lessor at its address as in this Agreement set out (or such other address as Lessee shall have last furnished Lessee in writing), or by serving same personally at the office of the Lessor. In the event Lessee and Lessor agree to continue this Agreement beyond its expiration date, the same terms and conditions will apply as specified in this Agreement.

20. The failure of either party hereto in any one or more instances to insist upon the performance of any of the terms, covenants or conditions of this lease, to exercise any right or privilege of this Agreement conferred or the waiver of any breach of any of the terms, covenants or condition of this Agreement, shall not be construed as thereafter waiving any such terms, covenants, conditions, rights or privileges, but the same continue and remain in full force and effect the same as if no such forbearance or waiver had occurred.

21. Lessor may assign this agreement along with collateral documents without prior consent of Lessee to financial institutions or security for any indebtedness of Lessee, and all rights, title and interest of Lessor in the agreement shall inure to the benefit of the assignee and its successors and assigns. The Lessee may assign use of any unit after receiving written approval from Lessor.

22. In the construction of this agreement the singular of any term shall include the plural and the plural of any term shall include the singular. Each gender shall include each of the other genders.

23. Upon the expiration, or sooner termination of this lease, the Lessee shall return and deliver said motor vehicle(s) to the Lessor at its place of business at 1025 Connecticut Avenue, N.W., Washington, D. C. in good order, condition and repair, reasonable wear and tear excepted. Any damage to said motor vehicle(s) shall be paid for by the Lessee to the Lessor. Tires shall have no more than 80% wear.

24. This Agreement has been executed in triplicate, each of the three copies being deemed to be an original. IN WITNESS WHEREOF the parties have hereunto caused these presents to be executed the day and year first above written.

EXECUTIVE AUTO LEASING, INC.

By: [Signature] Lessor

Epilepsy Foundation of America

By: [Signature] Lessee

Senator STAFFORD. Mr. Chairman, I came in late, and I apologize for that, because I had another commitment, but just so that I can understand maybe a little better what is going on, Mr. Funk, am I correct in assuming that your salary is \$41,983, and that in addition to that you got a \$12,000 bonus?

Mr. FUNK. Bonus would not be my word, but the figures are correct, sir.

Senator STAFFORD. So that actually your income from the Epilepsy Foundation of America is approximately \$54,000?

Mr. FUNK. No. It would have been about a total of \$48,000 for the first 2-year period that we are discussing, and would have been \$2,500 more for the second 2-year period.

Senator STAFFORD. That does not include any value on the use of the car that is made available to you?

Mr. FUNK. It does not.

Senator STAFFORD. Then do I understand also in 1973 the foundation realized a total income of \$3.5 million, according to the figures we have here.

Mr. FUNK. In 1972?

Senator STAFFORD. 1973.

Mr. FUNK. In 1973, that audit is not yet complete, but I believe that the figure will be slightly higher than that.

Senator STAFFORD. On the figures that are available to us, if \$3.5 million is not the accurate figure, the accurate figure might be a little higher?

Mr. FUNK. I would think so, sir.

Senator STAFFORD. On the figures available to us, the costs of producing that income to the foundation was \$1.460 million.

Mr. FUNK. That would be approximately correct.

Senator STAFFORD. Or 42 percent of the total amount of income; and the general management costs—

Mr. FUNK. Excuse me. I believe that 42 would not be the way I would calculate that. I believe that it would be a hair under 39 percent.

Senator STAFFORD. In any event, 42 percent is not very far off the mark, is it?

As I read the information available in front of me, general management costs were \$378,000. I assume that would be on top of the fundraising costs insofar as total overhead is concerned. Am I correct?

Mr. FUNK. That would be correct.

Senator STAFFORD. So that anyone contributing to the Epilepsy Foundation of America in 1973 could anticipate that a little more than half, that 51 percent of the total contributed, would be going to Epilepsy Foundation overhead, and only 49 percent would be actually going to the various activities of the foundation in connection with epilepsy.

Is that a fair statement?

Mr. FUNK. I think the figures are the other way around, but that would be a fair statement.

Senator STAFFORD. They are pretty close to accurate, whether it is 51 or 49 percent as overhead. Am I correct?

Mr. FUNK. Yes.

Senator STAFFORD. So for the understanding of a layman, half of his contribution does to overhead and only half of it reaches the purpose for which he might be contributing to the fund for the Epilepsy Foundation. Is that an unusually high amount of overhead to charge off against donations to a charity?

Mr. FUNK. I would like to pick it up, if I may, in two parts. One was the general and administrative or management that you talked about.

That figure in the headquarters is about 11 percent. I believe that would be comparable with most other similar organizations. Some are higher, some are lower. I would however say very clearly that the fundraising portion is higher.

Senator STAFFORD. Could I ask you, Mr. Funk, who does your fundraising for you? Does the foundation do it, or do you contract it out to somebody?

Mr. FUNK. No. The foundation does this work itself.

Senator STAFFORD. Then in effect you are paying yourselves the expenses of raising the \$3.5 million in 1972 and 1973?

Mr. FUNK. That is correct.

Senator STAFFORD. And you say that is unusually high.

Mr. FUNK. It is indeed.

Senator MONDALE. I wonder why that is.

Mr. FUNK. I have earlier suggested that it is directly related to the stigma that surrounds epilepsy.

Senator STAFFORD. Thank you. I have no further questions at the moment. Mr. Chairman.

Senator MONDALE. As you know, in addition to the question of fundraising costs, one of the first questions usually asked is "How much do you pay your chief officials?" People are very concerned that charity be a charity, in compensating persons who work for it. Why was not your \$12,000 payment received on two occasions, listed in your reports to the Internal Revenue Service and in your official statement to Illinois?

Mr. FUNK. Probably because it was set up on our records as a signing fee or consideration, and that the balance was set up as a salary. There would be no other reason.

Senator MONDALE. Is that a reasonable conclusion? Suppose you received \$50,000 for signing, and took a salary of \$20,000. Would it be fair to list \$20,000 as your income? I realize that is not what you did.

It seems to me the principle substantially understates your income.

Mr. FUNK. That certainly was not the intent. I would like to make it clear that when my compensation has been discussed by a board of directors I have not been in the room. I would like to make it equally clear that the contract is drawn up by legal counsel to the foundation, and I am certain that no one thought the proceedings unusual or anything other than what they should be.

Senator MONDALE. Is this a very standard contract in the charity field?

Mr. FUNK. I have no way of knowing, Senator.

Senator MONDALE. You said it was not unusual. What do you mean by that?

Mr. FUNK. What I said was that I do not think any of our board thought it was in any way unusual.

Senator MONDALE. Mr. Ennis, do you know whether any of your salary was included in the 1972 fundraising costs?

Mr. ENNIS. I believe, Mr. Chairman, that a few moments ago you asked me, and I estimated between 10 and 15 percent, and I believe it would be an average of that in 1972.

Senator MONDALE. You will be submitting records for that. That is your best judgment?

Mr. ENNIS. As Mr. Funk indicated, we have a spread sheet, and that, as I recall, it was somewhere in the 10, 11, 12 percent.

Senator MONDALE. And you have seen this?

Mr. ENNIS. Yes, I have.

Senator MONDALE. I hope you can get that.

According to your joint statement, Don Organ and other people in his community services department provided fundraising advice to chapters. Was a part of those salaries to those 12 people included in the 1972 fundraising costs and, if so, how much?

Mr. ENNIS. No, Mr. Chairman. At that time that division and allocation did not exist. This is a more recent decision by the executive committee and board, and would date back to about November or December of 1973.

Senator MONDALE. So in 1972 no part of the—

Mr. ENNIS. Some part.

Senator MONDALE [continuing]. Of the salaries of the community service department was allocated to fundraising; is that correct?

Mr. FUNK. I would be certain that they were giving advice and counsel to chapters, and whatever the National Health Council standards defines, that portion was reported as fundraising.

Senator MONDALE. I am a little confused. As I understood Mr. Ennis, he said in 1972 none of those services was allocated, and now I understand, Mr. Funk, you are saying they are allocated.

Mr. ENNIS. That is my error, Senator, I thought you were referring to the most recent decision as outlined in the statement.

There would be a portion of the 1972 field director's salaries allocated, thus some portion to fundraising. I thought you were referring to the recent statement.

Mr. FUNK. I think what Mr. Ennis was referring to was during the past year our board of directors have asked that people be put into our regions specifically to raise funds. The regional managers there heretofore have a wide variety of duties involving public information, education, involving linkages with medical installations.

Senator MONDALE. But it would be fair to say that some portion of that community services department is engaged in fund raising, would it not?

Mr. FUNK. Counsel to the chapter, yes.

Senator MONDALE. Would that not be then fairly allocable to fundraising costs?

Mr. FUNK. I would have to refer to the Health Council book. My recollection is that it would be. I am not certain of that.

Senator MONDALE. Mr. Smith, what did you do in this area in 1973?

Mr. SMITH. You are referring, Senator, to the chapter department people doing fundraising and their costs?

Senator MONDALE. I am referring to expenditure of funds under the category of community services, and to your document based on part of their time providing fundraising advice and assistance to chapters, and I am asking whether in 1973 in your presentation of the books some portion of those expenditures was allocated to fundraising costs.

Mr. SMITH. Those expenditures would be purely salaries, and let me bring a spread sheet which we have for 1973. I do not recall offhand.

Senator MONDALE. You cannot remember?

Mr. SMITH. No sir.

Senator MONDALE. According to your statement, General Shannon and eight people in his department have been engaged in processing contributions. Was the salary of those eight people and part of Shannon's salary included in the 1972 fundraising costs and, if so, how much?

Mr. FUNK. I would have to take a look at the records, but a part of that would be, yes.

Senator MONDALE. How much?

Mr. FUNK. What we are talking about is a room into which all our contributions come, and that is what? A half million checks a year?

Mr. SMITH. Probably more than that.

Mr. FUNK. The salaries of those people are carried—

Senator MONDALE. Would not that all be allotted to fundraising?

Mr. SMITH. No sir. We consider those processors to be the beginning of the accounting function, and those eight salaries are all charged to general and management.

Senator MONDALE. How much is spent on those eight people, approximately?

Mr. SMITH. Approximately?

Mr. FUNK. Approximately \$50,000.

Mr. SMITH. If you include the indirect benefit costs, such as pension, you may get it as high as \$70,000.

Senator MONDALE. You do not consider that fundraising when they open envelopes?

Mr. SMITH. It is also an accounting function of recording receipts. We have drawn a line between that function—which we consider accounting, general and management—and the point where the envelopes go to the computer to be placed on a tape; those charges are then fundraising costs.

Senator MONDALE. The National Health Council standards provides that its members report as fund raising all activities that constitute, or are an acceptable part of an appeal for financial support. Would not opening of envelopes be a part of raising money under that standard?

Mr. SMITH. Senator, also in the same standard it refers to a list of items which are general and management. One of them is accounting.

It has been our feeling that this is more of an accounting function of recording receipts than it is of fundraising.

However, you realize it would not change the total when you add the two support costs together. You are talking about the difference between fundraising and management in general, but it has been our feeling, that it is an accounting function.

Senator MONDALE. In other words, it is your judgment that none of that should be allocated to fundraising.

Let me return then to the community service department. Is any of that allocated to fundraising?

Mr. SMITH. Again, Senator, I do not know. I would have to take a look at the sheet.

Senator MONDALE. You remembered this one. Is this not sort of a key question in preparing accounts?

Mr. SMITH. I know one in part because it comes under my direct supervision. I do not know the answer to the question in large measure because the fundraising percentages in the ones that you have asked about are relatively small percentage of salaries, and I just do not know what those percentages are.

Senator MONDALE. Do you know whether any proportion of the community services department is allocated to fundraising at all?

Mr. SMITH. No sir, I do not know.

Senator MONDALE. Other than the people we have mentioned, and other than the people in the fundraising department, who else has been engaged in national fundraising activity?

Have your different regional managers been engaged in fundraising activities?

Mr. FUNK. They are involved in giving counsel and advice to the chapters.

Senator MONDALE. Would part of that be fundraising advice?

Mr. FUNK. Part of it would be fundraising advice; correct.

Senator MONDALE. Is any proportion of their salaries included in fundraising costs?

Mr. FUNK. My impression is that they are, but I would defer to Mr. Smith and to this rather thick and detailed book, which I do not have clearly in my mind.

Mr. SMITH. Again, Senator, I do not know.

Senator MONDALE. Mr. Ennis, would you tell us the name, title, and job of each person assigned to fundraising during 1972.

Mr. ENNIS. In 1972 Margaret Paul would be director of direct mail fundraising, and there would be a secretary, Mrs. Walker I believe; a statistician, Mr. Mahoney.

At that time, Senator, I think there were probably four people immediately involved in the so-called fundraising unit, so it would be a statistician, a secretary, Margaret Paul and a fundraising clerk.

Senator MONDALE. But you gave some names there.

Mr. ENNIS. Yes. Ms. Paul would be the unit head. There would be a secretary.

Senator MONDALE. What is her name?

Mr. ENNIS. Albertha Walker, as I recall.

Senator MONDALE. All right.

Mr. ENNIS. There would be Mr. Bill Mahoney, who is a statistician, and, again, doing this from memory, a fundraising clerk-assistant.

Mr. FUNK. I believe his name was Krear.

Senator MONDALE. How many months did each of these persons work in fundraising during the year?

Mr. ENNIS. I would think during 1972 the majority of the year, but I do not have the employment sheets.

Senator MONDALE. You had a Joseph Rizzo who was deputy director in charge of fundraising in October 1972.

Mr. ENNIS. Yes, that is correct. Mr. Rizzo was transferred from the public information and education department to fundraising, and I believe he was there a short period of time.

Senator MONDALE. How long was he there?

Mr. ENNIS. I would estimate a month or two.

Mr. FUNK. I think a little longer than a month—3 months, I would say.

Senator MONDALE. In October 1972 William Sutherland was hired to develop a foundation grant program. Who was Sutherland?

Mr. ENNIS. Mr. Sutherland did join the program at the end of that year, and he came into the nonmail fundraising portion of the program.

Senator MONDALE. I suppose we are just going to have to wait for your worksheets on the allocation of these expenditures.

Senator STAFFORD. Thank you, Mr. Chairman.

Mr. Funk, are the contributors to the fund made aware in any way of the fact that half their contributions are going to go to either overhead for raising funds or management costs of the foundation?

Mr. FUNK. They are made aware if they ask, Senator, or at least that has been the situation in the past.

Currently we have in the mail material designed in accordance with a bill in the House of Representative suggesting that that offer should be made on the letter.

We have two tests, one making the offer in conformity with that bill, which is not yet law. The other test, sends it along, and I have a sample of that with me here today.

Senator STAFFORD. Does that material that you speak of, which you say is being mailed out, advise the contributor that half of his contribution will go to overhead or approximately half?

Mr. FUNK. Yes. In my statement I include a letter from Representative Van Deerlin's office who is the sponsor of that legislation wherein he states this is exactly what he has had in mind, and commends the foundation for writing that.

Senator STAFFORD. We would like to see it now if we may.

In the meantime, Mr. Funk, how fully have you supplied this committee with the details of the costs of raising funds for the foundation?

Mr. FUNK. We have supplied the committee with each and every item requested by the committee.

Senator MONDALE. Is printing material for funds solicitation one of the major costs of your fundraising?

Mr. FUNK. It is the major cost.

Senator STAFFORD. How about mailing costs?

Mr. FUNK. Mailing costs I think are shown in the statement as a separate item.

Senator STAFFORD. How major an item is travel in connection with fund raising?

Mr. FUNK. Travel out of our basic 90 percent plus that comes from direct mail is a very minor item. It would involve primarily attendance by people doing that work at conferences. Fundraising in foundation solicitations; travel would be an item there because the foundations would be located in various cities.

Senator STAFFORD. I noticed in looking at one statement I had here, which may have been prepared by the foundation—I do not know whether it was or not—I am told it is your foundation information that in connection with one of your activities community services, the largest single item outside a grant to the National Children's Rehabilitation Center was \$123,000 for travel in 1972.

Is that not an awful lot of travel?

Mr. FUNK. Well, our regional managers are required to visit each chapter at least once during the year. For many of the chapters that are in the developing stages they visit more frequently, and the major cities in their regions they concentrate on.

The item is large, but they tell me that it should be much larger because they do not get around to see the local people as often as they think they should.

Senator STAFFORD. I note that your total costs for travel in 1972 were listed as \$148,896, and then I note that in 1971 your travel costs were \$109,273. In 1972, they were \$169,483, which means a \$60,000 or more than a 33 percent increase in costs in 1 year.

Was there some particular reason for that?

Mr. FUNK. The number of chapters, sir, has increased from 77, 3 years ago to 164 as of to date, and that would suggest to me that perhaps the travel correlates with that increase.

Senator STAFFORD. You might assume it costs about \$1,000 in travel per chapter per year.

Mr. FUNK. That would not be solely regional manager travel. That would be travel of other personnel to professional conferences. That would be travel to set up such conferences; it would be a lot of other travel in there.

Senator STAFFORD. Are all of the chapters that you just mentioned by number active at the present time?

Mr. FUNK. They are indeed. They are classified in various ways. We have different requirements for a full affiliate chapter and a provisional one which is on its way to filing those standards.

The information contact, which is a group of local concerned citizens distributing literature and doing referral—so there is a probationary period. All of the 164, to the best of my knowledge, are active and in the process of moving upward in the stages of development.

Senator STAFFORD. Thank you; and thank you, Mr. Chairman.

Senator MONDALE. Part of our difficulty here is that we are trying to establish specifically the way in which you allocate costs between fundraising and nonfundraising for the purpose of determining how actively the records disclose fundraising, because, as you know, American contributors are quite concerned that the money they contribute goes for the purpose they were solicited.

Your costs are quite high even based on your accounting methods, and the question is whether those accounting methods accurately reflect costs.

Our analysis of your books shows just in the fundraising department alone your staff costs ran over \$60,000 for the year 1972, and that is more than you show in salaries to be allocated to fundraising, which would mean if we are right that none of these matters that we talked about earlier—opening of envelopes when the money comes in, paying for community services, advice to local chapters in fundraising, other than the top executives in the foundation—none of that is allocated to fundraising.

I must admit, in fairness to you, we do not have the records, but I would hope that we might get those worksheets immediately.

Is there any chance we could get them this evening so we could take a look at them?

Mr. FUNK. Whatever we have, I see no reason why you should not have them immediately.

Senator MONDALE. You have worksheets for 1973?

Mr. SMITH. In percentage allocations, I have, yes.

Senator MONDALE. May we have those this evening?

Mr. SMITH. Yes sir.

Mr. FUNK. Senator, if I may, let me reconstruct 1972 just a little bit, which I think may help to arrive at the picture.

As Mr. Ennis has indicated, for most of the year there were essentially four people in the headquarters two assigned the fundraising. The highest salary paid to the four is about \$16,000. So I believe that \$50,000 would be correct.

Senator MONDALE. If \$52,000 is correct as a salary expense for fundraising, then it means that none of those other expenses—not your salary and not the salary for people opening envelopes and salary of people advising local communities on fundraising—none of that was included under fundraising salaries; is that correct?

Mr. FUNK. Certainly as Mr. Smith has testified, none of the salaries for people opening envelopes are in those figures.

Senator MONDALE. I do not think there is any point in kicking that around now, but I do wish we could get those worksheets so we could find out precisely how you arrived at the allocation of fundraising costs. If we could have at least the 1973—you must have the 1973 reports around somewhere. That seems to be almost a fundamental document in preparing that audit.

Mr. FUNK. I would also add this, if I may. In the new standards now being circulated by the Health Council, there is a suggestion for a new daily timesheet. We have that timesheet in effect, and it should very quickly clear up this kind of question.

Senator MONDALE. We would like to see those documents.

Mr. FUNK. That is under the new standard being circulated. There were not similar timesheets during the time frame we are discussing here.

Senator MONDALE. In which in your literature you have been suggesting you are dissatisfied with your direct mail fundraising programs, and you are working on ways in which to raise money that is more desirable.

What have you done to achieve that?

Mr. FUNK. Would you care to respond?

Mr. ENNIS. Yes. Mr. Chairman, we have been very dissatisfied with the disproportionate reliance upon direct mail, and we are making every effort, as Mr. Funk indicated, in the adjoining statement, to diversify our sources of funding.

Actually more in the last few months, perhaps in the last year, we are getting especially into the area of foundation support, various special benefits, special gifts, a rather limited commerce and industry drive, the type of fundraising that is generally done by most voluntary health agencies.

Senator MONDALE. But you testified earlier 90 percent of your money comes from direct mailing.

Mr. ENNIS. I would say yes. Mr. Chairman, 90 percent of our revenue would come from the direct mail source, but I think there has been an improvement.

If you will refer to the statement, on one page it indicates a slight but measurable lessening of that. It is on page 77 of the statement.

It indicates there are some areas such as foundations, major donors, and this refers to the unaudited figures for 1973, but I am sure they are relatively accurate within a tiny percent.

Senator MONDALE. Do you have anybody in your fund raising department who is an expert in raising money in any other way other than direct mail?

Mr. ENNIS. Yes; we have had at various times—I have been involved, as indicated; Mr. Sutherland has been involved in nondirect mail type activities. We have not historically been particularly strong in this area, but, as outlined in the statement, I think the reason of stigma, the much misunderstood difficulty of raising money for epilepsy has made direct mail more successful.

Although it is very hard to substantiate, this is my opinion, and the opinion of other people who have looked at the program.

Mr. FUNK. That would be my opinion. In the United States over 75 years there have been 30 attempts to form a voluntary health organization concerned with epilepsy. There have been many reasons why these have failed.

Primarily they have failed because of the inability to raise money, and it would also be my belief that the anonymity afforded the donor by direct mail is the reason why this particular form has become a method of the Epilepsy Foundation.

Senator MONDALE. In your fund raising letter you place great emphasis on research. According to your financial statement, about 5 cents of each dollar actually goes to research; is that correct?

Mr. FUNK. I would have to refresh my memory, but it would be somewhere on that order of magnitude.

Senator MONDALE. In direct research and treatment, what percentage of your total collected goes for that purpose?

Mr. FUNK. May I stay with just the research for a moment, because I have no figures set up by research and treatment.

Under this category those costs involved with our research professional advisory board team—

Senator MONDALE. As I see your 1972 report, you spent \$86,000 in awards and grants. Would that be a research program?

Mr. FUNK. That would be correct.

Senator MONDALE. That works out to about 2 cents from every dollar contributed.

Mr. FUNK. I have not done that computation.

Senator STAFFORD. Will the chairman yield?

Senator MONDALE. Yes.

Senator STAFFORD. Mr. Chairman, I have been examining the green sheet which Mr. Funk was kind enough to supply to the subcommittee on expenditures, receipts, I assume for 1973.

Mr. FUNK. No; those are based on our last report, which is 1972, out in 1973.

Senator STAFFORD. In any event, it shows totals of \$4,174,000 plus, and total costs of solicitations, administrative, managerial, and certain fixed costs at \$1.76 million, and a net income available of \$2,170,258.

Then the program expenditures, and it shows research at 8.1 percent of revenues allocated, which I assume would be the money available for programs, and that would only be about a little over 4 percent of the total \$4.17 million in revenues received by the foundation.

Mr. FUNK. That would be correct, sir.

Senator STAFFORD. So it is a little over 4 percent, Mr. Chairman.

Then I find the foundation material slightly misleading. The percent of the total income, which is allocated to programs, is not shown; the 100 percent figure that you have used applies only to those sources of revenue which are applied programs.

Mr. FUNK. To revenues available for programs, that is correct, sir.

Senator STAFFORD. It does not show the percent of the total revenue which is actually money available for programs. I would suggest maybe in the future you might want to include that, to fully inform your donors of what you are doing with their money.

Senator MONDALE. As I understand it, in 1972 you took in \$3.1 million.

Mr. FUNK. This would be in the national office.

Senator MONDALE. Yes; total receipts. Of that amount 13 percent went for research, and for direct grants to help children with epilepsy, is that right?

And if you consider the awards and grants which go for research, you consider the \$270,000 that goes to the National Children's Rehabilitation Center, and that comes out to about 13 percent of the total collected that actually goes for research, that goes for direct help to children or others suffering from epilepsy: is that correct?

Mr. FUNK. That would not be my definition, Senator. The parents of the children with epilepsy make very clear their concern as to the climate, their concern as to discrimination, and their choice for program dollars, and it is their choice on which our programs are based. They make clear that they believe that money should go for public information and education.

To that extent, all of those dollars aid that child.

Senator MONDALE. Let us throw in \$245,000 for public education That still gets you about 20 percent—19 percent.

Mr. FUNK. No; I would also add in several other items, including the professional education and training money which enables doctors to do a better job in treating the children.

Senator MONDALE. That is where we get back to the question of how that money is allocated, but it is true that in terms of research only about \$127,000 out of \$3.1 million received actually goes for research?

Mr. FUNK. That would be correct. The magnitude of the research problem I would like to make very clear—that the research into the epilepsies—perhaps Dr. Daly would say more about this.

There is no voluntary fundraising organization known to me, or none is in sight, that would be able to provide the magnitude of funds required for meaningful investigation into these disorders.

Senator MONDALE. As I see it, you spent \$86,702 on research grants, and you spent more than that on administrative overhead to administer the program.

Mr. FUNK. I think we have to take a look at what that administration is.

Senator MONDALE. Overhead for research.

Mr. FUNK. Under the Health Council standards that would be the category into which meetings of the professional advisory board would be accounted for, and those meetings would embrace the entire spectrum of professional subjects.

Senator MONDALE. Let us take a look at your fundraising literature here. It says:

Here is hope for these children, some 4 million suffering—and adults like them—from epilepsy. Grants from the Epilepsy Foundation right now are supporting long-range research which may finally lead to a cure for epilepsy. In the meantime your pennies can provide money for other research that helps right now.

Here we get a \$2 to \$3 investment in research public training programs which will help many thousands of epilepsy patients.

You say 4 percent of your money is going into research. Do you think if you said in this letter that 3 cents out of every dollar you send in will go for research you would get much money?

Mr. FUNK. I do not know if I were to say that. I think there are a great number of other things I would say.

Senator MONDALE. All right, tell us what else you would say.

Mr. FUNK. I think I would try to provide considerable more detail on the number of grants, the way in which the grants are evaluated, and the results that have been obtained from them.

Though the figures are small, a significant number of the papers presented at the American Epilepsy Society meetings have been on projects funded by the foundation.

Senator MONDALE. Can you tell me a little about the National Children's Rehabilitation Center?

Mr. FUNK. Yes, the center is at Leesburg, Va. It has a patient population at any given time of approximately 50. It is a residential facility.

Senator MONDALE. How many children are there?

Mr. FUNK. At any given time it is about 50.

Senator MONDALE. How many have epilepsy?

Mr. FUNK. All of them have epilepsy.

Senator MONDALE. Are you sure of that? We have a different report.

Mr. FUNK. In the literature of the center the admissions criteria are set forth very clearly.

Senator MONDALE. Does Dr. Daly know? Are you in a position to comment on that?

Dr. DALY. I do not have anything to do with that, Senator.

Senator MONDALE. Our report says that the program is heavily psychotherapeutic, and according to Mr. Higby—who is the director—epilepsy is nearly incidental at the center. They accept socially and emotionally handicapped children with normal intelligence only, and the focus is on emotional illness.

I want to be fair. Maybe you are right, but our reports indicate that may not be correct.

Mr. FUNK. No, I think they are correct, Senator. The center focuses in on psychotherapy and adjustment, but of children with epilepsy.

Senator MONDALE. Your understanding is they must be epileptic?

Mr. FUNK. That is indeed my understanding.

Senator MONDALE. Would you double check and just be sure?

Your reports indicate you spent about 8 cents in 1972 of each dollar on public health education. In one of your pieces you called it the No. 1 priority. What does this mean? What do you do?

Mr. FUNK. We do a wide variety of things. Let me start with the consumer literature. I believe that samples of that are available in the committee room.

[The following publications were submitted to the subcommittee:]

"Answers to the Most Frequent Questions People Ask About Epilepsy"

"Because You are My Friend"

"Consensus—A Compendium of What Is Believed To Be The Majority Professional View on Several Key Questions About Epilepsy"

"Epilepsy School Alert"

"Facts and Figures on the Epilepsies"

"History of the Epilepsy Movement in the United States"

"Medical and Social Management of the Epilepsies"

"National Directory of Chapter Program Services"

"Pharmacopoeia of the Epilepsies"

"Recognition and First Aid for Those With Epilepsy"

"Spectrum—A Compendium of Current Opinion and Fact on Several Key Questions About Epilepsy"

"National Spokesman (March 1974)"

Mr. FUNK. These are the most frequent questions asked by patients and parents, and these are our answers [witness holding up pamphlet.]

"Research into the Epilepsies" tells what is being done by the Federal Government, by us, by medical schools.

[Witness holding up second pamphlet.] This is an up-to-date report on the state of the art.

[Witness holding up a third pamphlet.] "Because You Are My Friend"—this is designed for the child with epilepsy to tell that

story to schoolmates and people, as to how to break the news that he has epilepsy, and how one would react to it.

The next pamphlet indicates to what extent and in what ways can epilepsy be prevented. This talks of the head trauma which is far and away the prime cause of epilepsy.

We are very active, we are a sports-minded Nation, and a great deal of epilepsy comes from automobile accidents and sports activities. This talks to what our hope is for preventing it.

Our next pamphlet is "Pharmacopeia of the Epilepsies" which outlines the drugs used in chemotherapeutic management. There are 20 to 30 pamphlets developed according to questions we are being asked. That is one activity.

Another activity is a monthly newspaper which goes to city, State, county, regional health agencies, doctors, social workers, keeping them advised of the latest developments in the field.

We have an inventory of about 13 TV messages which we provide to TV stations across the country. We have I think about eight exhibits which we make available to the chapters which we ourselves use at the variety of conferences.

There is a film library which distributes films to luncheons, clubs, nursing schools—a wide variety of people who ought to know more about epilepsy.

In that total would be all of the tools of information and education, about 300 projects a year which are done by that department.

Most of that activity peaks up in November, which is epilepsy month, and there is a wide variety of materials provided to use by radio stations, TV stations.

Still another activity is the encouragement of writers and authors to write articles on epilepsy. There is an annual journalism award activity.

I think perhaps that gives the highlights. We work with producers of TV shows. We work with magazine editors.

Senator MONDALE. It is now noon, and I have just a few more questions, and hopefully we can reconvene here tomorrow morning, but I hope we can have for our use these breakdowns.

One thing that came to my attention was, as I understand it, you indicated in your newsletter that the staff of the national office has been averaging about 60 people. I have a list of some 57 employees who left the organization between January of 1973 and January of 1974. The great majority of them were with the organization less than 6 months.

As we read your record you paid \$55,000 to employment agencies in that year alone to find people to keep your office running. What explains this astounding employee turnover?

Mr. FUNK. I am not certain that those figures are entirely correct, Senator.

[Paper was handed to the witness.]

Mr. FUNK. At the beginning of 1974 our board in assessing the economic climate for the year asked that we reduce staff by, as I recall, 14 people.

Senator MONDALE. This is 1973-74; right?

Mr. FUNK. Right. So that would account for the first 14.

The list in front of me—some of the names I do not believe are within the time frame, if you want them.

Senator MONDALE. We have the name of a Roberts who was with you for 4 months.

Mr. FUNK. That is correct.

Senator MONDALE. We have Jeffrey Honig, for 5 months.

Mr. FUNK. That is correct.

Senator MONDALE. We have Brenda Smallwood, 2 months. We have Sylvia Ker for 2 months; Marcia Landau for 4 months; William Mullen for 6 months; Babitz for 6 months.

Mr. FUNK. Babitz began with us as a freelancer and is currently a freelancer. She works on the pamphlets that we referred to earlier.

Senator MONDALE. In other words he is not on the payroll?

Mr. FUNK. Babitz is a she.

Senator MONDALE. She gets consulting fees.

We have a Kendrick, 4 months; Daniels, 3; Wesman, 2; Hughes, 6; Adler, 6; Chase, 10; Blattner, 4; Nesterrik, 8; Forche, 8; Hatlestad, 4; et cetera.

What explains this turnover here?

Mr. FUNK. Well, in the first place, I don't think the names and the time frame are accurate.

Senator MONDALE. You paid \$55,000 in employment fees in a single year. That is more than you spent on salaries for research.

Mr. FUNK. I do not recognize that figure, Senator. We have had heavy employment fees in the past year. We have been looking for some very highly specialized, qualified people. Mr. Smith was one of those. Dr. Perlman, who heads our Government liaison and program development department, who comes to us from NIH, is one of those.

I think the figure in the current year indeed is a heavier one than normal figure.

Senator MONDALE. Can people accomplish for you the objectives of your program when they are only there for 2 or 3 or 4 months?

Mr. FUNK. No. That is why all people who join us do so far a probationary period of 3 months.

Senator MONDALE. It is a highly risky period. I don't understand it. It looks like a tremendous amount of turnover.

Mr. FUNK. I believe that the subcommittee staff raised this question at considerable length, to the best of my knowledge. Even assuming that these figures are correct, they would be under similar figures that I believe to be available on turnover.

Senator MONDALE. We would be glad to have anything else that you want to submit for the record in this. Our figures show \$55,000 in fees paid during this period to hire 40 people, and 20 of them are still with you. That is in 1973.

Mr. FUNK. The figure from the U.S. Department of Labor I believe which shows 44 to 49 new hires per 100 people as the U.S. average for all nondurable industry activities.

I am not acquainted with every other base that would be used for comparison purposes.

Senator MONDALE. How long have you been a member of the board, Dr. Daly?

Dr. DALY. Since its inception, Senator.

Senator MONDALE. Have you been a member of the executive committee?

Dr. DALY. Yes.

Senator MONDALE. How intimately involved are you in the operations of the foundation as a member of the executive committee?

Dr. DALY. I do not know how to answer that specifically.

Senator MONDALE. How often do you meet? How detailed are your activities?

Dr. DALY. The professional advisory board meets twice a year. The executive committee meets once or twice a year.

In terms of personnel and salaries, I have nothing to do with that. There is a policy that was recommended by the executive committee that in terms of recruitment we felt the salary should match proportionately the salary of the largest employer in this area, which is the Federal Government, and I believe that policy has been carried out.

I would like to answer a question that was not specifically directed to me, but I think deserves some answer. This is a matter Senator Stafford raised about research funds.

There is about \$5 million a year in research funds in the area of epilepsy, and the vast majority of that comes from the Federal Government, and probably the largest single amount through the National Institute of Neurological Diseases and Stroke.

It has been the impression of many of us that there are two areas where there is need of help. There is need to attract more investigators into the area of epilepsy for research. It is very difficult to get young scientists to go into this area for whatever reason and, second, it is difficult for relatively new investigators to be funded, particularly in competition through the grants program of NIDS.

The figures that we arrived at as a level of support for research were based on the postulate of one trying to have summer fellowship programs for medical students to get them working in a medical laboratory with somebody so they would become attracted to this field and, secondly, to provide small grants.

Senator MONDALE. Dr. Daly, we hope to get into the programmatic problems in epilepsy. I think everyone agrees this is a tragic disease. I would like to get into the business management of this foundation and your role as a member of the board.

Were you aware, for example, that they had an extraordinarily high employee turnover?

Dr. DALY. No. That is not in my province.

Senator MONDALE. That is not within your province?

Dr. DALY. No, sir.

Senator MONDALE. What do you consider to be your province as a member of the board?

Dr. DALY. I consider my concern to be, first of all, with trying to define programs.

Senator MONDALE. So you do not concern yourself about the business operation?

Dr. DALY. Other members of the board, Senator, are better qualified in terms of economics than I am; yes.

Senator MONDALE. Under the law you must be aware that as a member of the board you have responsibilities.

Dr. DALY. Yes, sir, I am aware of that, but I think you would agree that probably if somebody in the accounting area tried to advise me about what was the appropriate research approach, that probably that advice would not be as useful as my opinion.

Conversely I think I rely on the members of the executive committee who are far better qualified than I am in such matters.

Senator STAFFORD. Mr. Chairman, before we close may I ask one more series of questions.

Senator MONDALE. Certainly.

Senator STAFFORD. These bring me back to what troubles me somewhat.

The community services category of the program of the foundation, because under your 1972 sheet it shows that your expenditures here were \$902,450, or the largest single factor I think in program expenditures, and yet of that total in 1972 of \$900,000, Doctor, were you aware that \$267,000 went for salaries, \$18,800 went for employee benefits and payroll taxes, \$9,000 went for employment costs; \$21,000 for rents and utilities; \$123,000 for travel and meetings; \$6,800 for office services; \$9,000 for telephone; \$16,900 for printing, \$36,220 for professional fees; \$20,000-some-odd for postage and shipping; \$698,000 for data processing, and \$39,800 for assistance to affiliated local chapters; and \$1,700 for miscellaneous which does not leave an awful lot for awards and grants or films and visual aids or research.

It did leave \$270,000 for grants to the National Rehabilitation Center, but the bulk of that money went to internal costs, salaries, and so on within the foundation.

I wondered if you were aware of all of this.

Dr. DALY. You ask me if I am aware of the dollar figures, as you read them off to me. Of course I could not recall them specifically, but I have been over the budget at meetings of the executive committee, yes, sir.

Senator STAFFORD. I think the record should show the figures produced are those of the foundation and not figures produced by this subcommittee.

Dr. DALY. I understand. What I meant, as you read the list to me, I would not know whether that was an accurate number.

Senator STAFFORD. The thing that impresses this Senator is that so high a percent of this category of expenditures in your program goes to what I would think of as simply overhead of operations, and not actually to doing any constructive program on behalf of the children that it is intended to benefit.

Mr. FUNK. May I speak to that?

Senator STAFFORD. Certainly.

Mr. FUNK. The expenditures you list in the community services area, which is the chapter development area, are, I believe correct.

We have put our emphasis since our inception 5 years ago on the building of a network of local chapters across the United States, believing that no national office can hope to cope with the massive problems of the epilepsies.

We believe these will be solved at the local level and in the local communities. That has indeed taken a disproportionate share of our

funds, and we have put an awful lot of effort in increasing those 77 chapters to 164. We believe that once those units are in place and in putting them into place we have coped with a number of problems, some of which I mentioned here—some people fear to be identified with that local organization lest their friends think they have epilepsy.

There is a penalty in our society for being so identified. That has been a costly venture.

We believe that we probably will have another 2 years of building that chapter system. We see some results. As of a year or so ago in the field as contrasted toward our headquarters, there were 51 paid people, paid for by the local communities. Today there are 138.

As we look down the road, it is here that the growth of the foundation will come, and we are in the early investment stages of putting together a network across the country where the people are to take care of people with epilepsy in those communities.

Senator STAFFORD. Thank you for your statement. I think that is all at this time, Mr. Chairman.

Senator MONDALE. We hope this evening that we can get those worksheets. We would like if your schedule permits to resume at 9:30 rather than at 10 o'clock tomorrow. It will not be necessary for Dr. Daly to return.

Thank you very much.

[Whereupon the subcommittee recessed at 12:20 to resume at 9:30 a.m., Tuesday, April 9, 1974.]

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CHILDREN'S CHARITIES, 1974

TUESDAY, APRIL 9, 1974

U.S. SENATE,
SUBCOMMITTEE ON CHILDREN AND YOUTH
OF THE COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 9:40 a.m., in room 4232, New Senate Office Building, Hon. Walter F. Mondale, presiding.

Present: Senator Mondale.

Committee staff members present: Ellen Hoffman and A. Sidney Johnson III, professional staff members, and Harvey Katz, consultant.

Senator MONDALE. The subcommittee will come to order.

Will the panel consisting of Mr. Funk, Mr. Ennis, and Mr. Smith please return to the witness table.

STATEMENT OF PAUL E. FUNK, EXECUTIVE VICE PRESIDENT OF THE EPILEPSY FOUNDATION OF AMERICA, ACCOMPANIED BY THOMAS M. ENNIS, EXECUTIVE DIRECTOR, AND H. LEROY SMITH, CONTROLLER

Mr. FUNK. Mr. Chairman, if we may proceed, we have with us this morning all of the data I believe that you requested in yesterday's session. Dr. Daly is not with us this morning. His affairs necessitated that he return to Dallas.

I am sorry that the time did not permit him to talk about some of the important professional subjects and the program services provided to children and patients by the Epilepsy Foundation of America [EFA] chapters across the country.

On behalf of him, Dr. A. B. Baker of the University of Minnesota, and Dr. Adolph Sabs from the University of Iowa, he has requested that this brief summary on professional matters be incorporated into the record.

Senator MONDALE. It will be.

[The information referred to was not available for inclusion in the record at time of printing.]

Mr. FUNK. He also asked that I call your attention to this pamphlet which lists city by city the counseling, treatment, and employment and vocational rehabilitation services delivered by EFA chapters, including parental counseling to help parents better understand the growth and development problems of their children who have epilepsy; low-cost drug assistance programs; and many other programs.

With your permission I would like to ask that the table and the program descriptions also be added to the record.

Senator MONDALE. The staff will go over these materials. Some will go in the record and some will go into the official file.

Mr. FUNK. Yesterday you asked that I confirm the admissions criteria in effect at the National Children's Rehabilitation Center, and the director of that facility confirms that what I told you is correct. He has authorized me to reaffirm the description of the center as contained in its literature: a residential treatment center for the epileptic child who has emotional or social adjustment problems.

It is the goal of the center to return the children to their communities as functioning members of society. To this end therapy, counseling, and education are combined to create a comprehensive approach to each child's problem.

One of the directors of the center, a distinguished attorney from Washington, is also in the Chamber this morning, Mr. Thomas E. Jenks.

Yesterday you asked that we detail the cost of solicitation letters, and I submit that breakdown at this time, and with your permission would like to read aloud from it.

In 1973 mailings to our house list, the average cost was \$48 per thousand, which was made up of 1.7 cents postage; \$0.61, seals, \$0.36, letters; \$0.90 envelopes; \$0.49, reply envelopes; \$0.74, assembling; \$0.04, computer service; for a total of 4.84 cents per letter.

The 1973 mailings to outside potential donor lists average cost was \$72 per thousand, made up essentially of the same element plus the penny, plus name rental and exchange, and I have those sheets on the tables in the back there.

Senator MONDALE. What is your fundraising cost percentage on your latest house list? What did it run?

When you ran your house list letters, what percentage is consumed in mailing costs?

Mr. FUNK. It would be a lower cost ratio.

Senator MONDALE. Do you know what it is?

Mr. FUNK. I would defer to Mr. Ennis.

Senator MONDALE. Do you know, Mr. Ennis?

Mr. ENNIS. I do not know, Mr. Chairman. I would have to have the data with me to refer to. I might have to seek that information from the direct mail department.

Senator MONDALE. If it costs the 7 cents-plus for a letter to a potential donor, then I assume the return is much lower than on the house list. If the cost of fundraising on your potential donor list must run into what, do you have any figures there?

Mr. ENNIS. I am sorry. I could not hear you. Any figures on the cost of the donor list?

Senator MONDALE. Yes. What is the average size mailing to a potential donor list, a prospective list?

Mr. ENNIS. It might be anywhere from at the most a few hundred thousand, and the house mailing probably an average, might be 3 times that amount, maybe 900,000 or so.

Senator MONDALE. Your house list is about how much?

Mr. ENNIS. In any given average mailing, for example, the first house mailing for 1974, scheduled for January 5, 1974, was 900,000.

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Senator MONDALE. 900,000?

Mr. ENNIS. Yes.

Senator MONDALE. Then your new list would be what?

Mr. ENNIS. Anywhere from maybe 100,000, 200,000, perhaps more or less, depending upon the particular mailer list.

Senator MONDALE. Last year you have figures. What was the percentage return on your nonhouse list return?

Mr. ENNIS. In this statement the average gift—but that would include—for 1972 was 3.04.

Senator MONDALE. You mean you get about 3 percent return?

Mr. ENNIS. Yes.

I am sorry; 5.8 percent return for 1972, but that would be a combination figure, and for 1973 it would be 5.5 percent return—average return.

Senator MONDALE. That is from that new list?

Mr. ENNIS. That would be a combination figure, Senator. I suspect that would include both the prospective and the house mailing.

Senator MONDALE. What I am trying to get at is the percentage of proceeds consumed in the cost of mailing for your house list as compared to the percentage of cost consumed in your potential new list mailing.

Mr. ENNIS. If I may, Mr. Chairman, let me refer to the written statements submitted by Mr. Funk. I believe that I have that listed.

On page 93 of the written statement submitted by Mr. Funk yesterday, if I may just read this—this is for 1973—"During 1973" this in on page 37—

our mail efforts directed to EFA's current donors yielded approximately \$1,315.00. These mailings cost \$248,000 to produce and deliver, or only 18.9 percent of the amount raised. Epilepsy Foundation of America (EFA) faces, as do other similar organizations, the high cost of obtaining new names to replace those donors who, for a variety of reasons, leave a house list. In 1973 EFA spent approximately 64 cents of every prospect list dollar received to acquire new names.

Senator MONDALE. In other words, in 1973 your house list consumed about 20 percent of the amount raised in fundraising costs, but your new list, your prospect list, 64 percent—

Mr. ENNIS. No; it was 64 cents out of every dollar.

Senator MONDALE. 64 cents out of every dollar received.

Mr. ENNIS. The same equivalent; right.

Senator MONDALE. Where do you get those lists? Do you rent them?

Mr. ENNIS. These lists are exchanged or rented; yes.

Senator MONDALE. You mean you will swap lists.

Mr. ENNIS. On an even number exchange. Often, for example, another voluntary health organization with some disorder will exchange on a name-for-name basis.

Senator MONDALE. Do you find that people who give to one health charity are likely to be good prospects for another?

Mr. ENNIS. I believe so. There seems to be potential for donors who have a general health interest.

You might be interested—on pages 4-7, at the top of the page—our donor list indicate a previous cost ratio of \$0.50 on the dollar

and commercial lists, a previous cost ratio of \$0.75. A business-type list would have 75 cents on the dollar, which is very high.

But I understand from both profit and nonprofit direct mail experts that this is just about average for what the industry, both on the profit and nonprofit, has an experience. So therefore our experience is probably a little better than the average, if you look at the total figure.

Senator MONDALE. Yesterday I asked for the allocation sheets or breakdown sheets showing how you allocate costs among various operations, including fundraising for 1972 and 1973.

We have received a tentative breakdown sheet for 1973, prepared in October 1973, and some other data, all bearing on 1973; but we have received no data on 1972.

Would you tell us why that is not available?

Mr. FUNK. I have asked Price Waterhouse if they have working papers, Senator, and they tell me they do not. They tell me that these papers would not be required beyond the point where they have certified the allocations.

Senator MONDALE. They say they have no worksheets?

Mr. FUNK. That is correct. However, you asked yesterday that detailed salaries allocated to fund raising in our 1972 annual report, what they would be, and working with other records, and to the best of our knowledge and belief, we have reconstructed these costs by individuals, and I submit that estimated reconstruction to you at this time.

Senator MONDALE. I will take it.

Upon what were those reconstructions based? What documents and records were used?

Mr. FUNK. Our knowledge of who was working on what between what periods of time.

Senator MONDALE. In 1972?

Mr. FUNK. Yes.

Senator MONDALE. We would like those if we may have them. Do you have records that show how that was allocated?

Mr. FUNK. We have records that I would not call precise timesheets, but we do have a variety of assignment sheets, project sheets, and indeed weekly timesheets.

Senator MONDALE. Here we have for 1973 a preliminary 1973 budget, and we have a document here which breaks it down employees salaries by categories of effort. You must have something like that for 1972, do you not?

How could you prepare your audit if you did not have it?

Mr. FUNK. We did indeed up until the time we prepared the audit. After the audit had been certified, we feel it serves no useful purpose to retain that material.

Senator MONDALE. Mr. Smith, in preparing the allocations for 1973 did you discuss how that should be done with anybody?

Mr. SMITH. Yes sir.

Senator MONDALE. With whom did you talk?

Mr. SMITH. To General Shannon.

Senator MONDALE. What did he tell you?

Mr. SMITH. He suggested the allocations based upon his experience with the function of the person and the job.

Senator MONDALE. Did he have any sheets or data to work from that you saw?

Mr. SMITH. Not that I saw.

Senator MONDALE. You saw no 1972 allocation sheets at all?

Mr. SMITH. No sir.

Senator MONDALE. What did you do, just sit down, and he told you how to allocate the staff time?

Mr. SMITH. Yes, sir. He was the one who brought up the allocation.

Senator MONDALE. Was that all done orally?

Mr. SMITH. No, sir. We did it in writing. That is what this August change was about. The August statement, the last one—the type one—started with this first sheet, and was adjusted apparently from changes in our efforts, and the function people are performing.

Mr. KATZ. Mr. Smith, according to the preliminary 1973 budget, you gave us, that was prepared in October 1972, EFA was planning to allocate one-third of General Shannon's salary to fundraising which came to \$8,217, and one-third of his secretary's salary, which came to roughly \$3,000, which adds up to \$11,277.

According to this estimate you gave us here, none of General Shannon's salary was allocated to fundraising in 1972. Do you know why that was?

Mr. SMITH. No, sir, I do not.

Mr. KATZ. Does anyone?

Mr. SMITH. I would say it was because he did not feel he has a mail fundraising function.

Mr. KATZ. This sheet was prepared in October 1972. How could he be doing no fundraising at all in 1972, while it was planned that he would be doing a third fundraising in 1973?

Mr. FUNK. I think I can explain that. That was about the same period I understand that we moved into the fundraising unit two people, Mr. Rizzo and Mr. Sutherland.

I assume that the General, with those two people in place, removed himself from the picture.

Mr. KATZ. I would assume that too, Mr. Funk. Therefore a third of his salary should have been at least—perhaps more than a third—allocated in 1972 because this preliminary 1973 budget was a prediction of how General Shannon would be spending his time in 1973.

Since it shows a third of his time would be expended on fundraising, it seems to me, a lot more of his time was spent on fundraising in 1972. Yet on this sheet you gave us none of his time was allocated to fundraising.

Mr. FUNK. That is the allocation we did by reconstruction.

Senator MONDALE. Where did you get the information for the allocations in fundraising of salaries that you had here in the documents you gave us this morning? What was the source of that?

Mr. FUNK. This sheet?

Senator MONDALE. Yes.

Mr. FUNK. The source was Mr. Ennis, myself, Mr. Smith, such files as we could find late last night, and our very best estimate as to what the figures are.

Senator MONDALE. Was it basically recollections or is it basically data reflected in books?

Mr. FUNK. Basically recollections, Senator, with the confirmation being the overall records as to who was aboard during certain periods of time.

Senator MONDALE. What kind of books or data do you have to confirm this, or do you have nothing?

Mr. FUNK. The records as to who was aboard would come from our payroll records.

Senator MONDALE. We did not ask you who was working for you. We asked how you allocated salaries for fundraising and nonfundraising.

Mr. FUNK. Based on our knowledge of what the duties of those people had been when they were with us.

Senator MONDALE. So that is purely recollection?

Mr. FUNK. Yes, sir.

Mr. FUNK. Yes, sir.

Senator MONDALE. You say you called Price Waterhouse yesterday.

Mr. FUNK. Yes.

Senator MONDALE. What did they tell you?

Mr. FUNK. They told me that they have no allocation sheets that have survived the completion of the audit.

Senator MONDALE. Do they have any books or records left from that audit?

Mr. FUNK. Oh, yes.

Senator MONDALE. But they throw away the allocation sheets?

Mr. FUNK. I do not know what they did. I described what you were asking for, and they told me they did not have those. I would suggest that perhaps we could arrange for one of the partners in Price Waterhouse to answer those questions.

Senator MONDALE. We may want to do that before this is over.

Does the National Health Council come and audit your books?

Mr. FUNK. No sir, they do not. We submit a report to the National Health Council yearly to a set format, and that is reviewed.

Senator MONDALE. And one of the key questions that they determine is whether in your reporting of fundraising costs there is an honest and fair allocation to fundraising; is that right?

Mr. FUNK. Correct.

Senator MONDALE. How would they possibly know that if you throw away those records?

Mr. FUNK. The records, Senator, have been certified by Price Waterhouse.

Senator MONDALE. The National Health Council, as I understand it, is a voluntary organization that is designed to protect the public; and if an organization is affiliated with it, the public is supposed to have confidence in the documents issued by its constituent charities.

One of the key points is whether fundraising costs are accurately reported. I find it very very strange indeed that these records are unavailable. They had to be available in the preparation of these reports—No doubt about it—and I find it very hard to believe that there are not books that reflect precisely how this money was allocated, and if they do not, then I think we need a law.

I want to find out what the National Health Council is going to be doing—they are going to be testifying later—because the whole issue here is whether the public is being told the truth about how high fundraising costs are, not just to this charity but to all of them.

All I am getting is a murky big black cloud, and I find it very strange indeed.

I am going to find out what is happening here, and we may have to issue some subpoenas, but I am going to look through those books. I am going to find out what on earth is happening to this money.

Are you sure you do not have any records that tell us what happened to those 1972 costs?

Mr. FUNK. Senator, I have submitted the certified audited figures.

Senator MONDALE. Which do not tell us how you allocate the money.

Mr. FUNK. The purpose of the certification was to certify that we had allocated the money properly. The books and records we have at the foundation we have freely made available to the subcommittee.

Senator MONDALE. Yes. We were told you had allocation records. And then they disappeared. What happened? You said you had some upstairs.

Mr. FUNK. I am not acquainted with who gave you that information.

Senator MONDALE. My staff asked for the allocation records, and they said, "Well, we have them upstairs"; and then they could not find them.

Mr. FUNK. May I ask who gave that answer?

Mr. KATZ. I did. Mr. Smith, you said that you had these worksheets upstairs. Maybe we have a communications problem.

Mr. SMITH. If I did, that was not true, and I did not remember saying that I had those records; no sir.

Mr. KATZ. There is a tape recording—maybe we should listen to that.

Senator MONDALE. Here we go again. [Laughter.]

Mr. SMITH. I understand that exists. To the best of knowledge, I do not remember having said I have seen something which I have not seen.

Mr. KATZ. It is possible we are mistaken.

Mr. FUNK. Perhaps, Senator, some of this confusion, if it exists, will be alleviated by the new Health Council standards which are now being distributed which call for time sheets.

We ourselves have put into effect daily time sheets under the same reporting classifications. If this has been a problem, it should cease being one very shortly.

Senator MONDALE. We have your worksheets from 1973, Mr. Smith. They show that none of Mr. Funk's salary was intended to be listed as fundraising, even though he says he spends 5 percent of his time on it.

For 1973 it shows that none of Mr. Ennis' salary was listed as fundraising, even though he testified that 15 to 20 percent of his time was spent on this.

None of the salaries of the five regional managers was listed under fundraising, even though Mr. Funk testified they were supplying fundraising advice to chapters.

None of the salaries of Mr. Organ and people in his department were listed under fundraising, even though Mr. Funk testified that these people were providing fundraising assistance to the chapters.

As you testified yesterday, none of the staff salaries of the eight people opening envelopes on return from mail solicitations is listed under fundraising; is that correct?

Mr. SMITH. With the exception of Mr. Ennis, who I believe is on here for 30 percent, I think that is correct.

Mr. FUNK. May I clarify?

Senator MONDALE. Let us just see where Mr. Ennis is on there.

Mr. ENNIS. I believe I am on there for 30 percent.

Senator MONDALE. We have August 1973 allocation, Mr. Ennis, 35 percent for research, 1 percent public health, 35 professional education, 20—and nothing for fundraising.

Mr. SMITH. For Mr. Ennis I believe it is 30 percent.

Senator MONDALE. Oh, this is July.

Mr. ENNIS. I am on there for 30 percent, Mr. Chairman.

Senator MONDALE. In August you are. In July you are not. How do you explain it?

Mr. ENNIS. This indicates, Mr. Chairman, that my assignments changed. For example, as I indicated yesterday, I estimated 10 to 15 percent of my time in 1972 would be allocated to fundraising. At various portions, I gather the latter part of 1973, it would be to 20, 30 percent, the reason being, as I indicated yesterday, as needs change, my assignments change.

Presently, 1974, the allocation of my salary toward fund raising would be considerably more, possibly 60 to 70 percent, and I would say in August it would drop down to maybe 25 percent again.

Senator MONDALE. Mr. Funk, you are listed as having allocated none of your time in the July or August.

Mr. FUNK. I have asked our accounting department about that. My recollection was and is that I devote about 5 percent, and they have explained that to me.

Where I personally write fundraising material, they change it to fundraising. Where I am giving instructions, general management instructions, to the people running the department, they record it as general and administrative.

Senator MONDALE. Why were none of the five regional managers listed under fundraising?

Mr. FUNK. Their duties in regard to fundraising have to do with reviewing chapter fundraising plans. That time is recorded under the same category as they record their management audits of the chapters. It is only when they personally undertake fundraising that their time is recorded in that fashion.

Senator MONDALE. In other words, they are providing local chapters advice on fundraising, but that does not show up in fundraising.

Mr. FUNK. No, it shows up under a management function.

Senator MONDALE. It is your position then that where your national staff provides fundraising advice to local chapters that is not fundraising costs.

Mr. FUNK. We have been construing that, sir—and I hope correctly—as a management review function.

Senator MONDALE. It goes into community services, as I understand it.

Mr. FUNK. Right.

Senator MONDALE. It seems to me there is a bias against including things for fundraising in your reports. I would like to know how these decisions are made, and under what standards, and we find it is very hard to do when we do not have the allocation sheets except for these 2 months.

Could we be authorized to look at the Price Waterhouse record to determine what kind of allocation records exist, if any?

Mr. FUNK. Yes sir. In the testimony given by Mr. Grimes on February 4, I think he addressed himself to the difficulty of precisely reporting all of the agencies' expenditures for any single function, whether it be fundraising, management in general, or a particular program service. I think the point that he tried to make is that these are interrelated which makes that judgment most difficult.

Senator MONDALE. But it is kind of like the butcher, who always makes a mistake in his own favor. I do not see any evidence that the public's concern about what fundraising costs—and that is a very valid concern, I am sure you would agree—you say the eight people in that office opening envelopes when the money comes in is a management function; that is not fundraising.

Mr. FUNK. We call that accounting.

Senator MONDALE. Yes. So you say the five regional managers that go around and spend a great deal of their time advising local chapters on fundraising is not fundraising; that is professional services.

Your books here indicate insofar as allocations for 1973 are concerned, none of your time is allocated to fundraising.

Mr. FUNK. My directions to the heads of that department are recorded as management.

Senator MONDALE. Yes. That is all recorded, but I see in every case where there is any job it goes into a nonfundraising category, it seems to me.

Mr. SMITH. It appears to me that without time sheets, of course this becomes a matter of estimation and judgment, and this is the reason why we have suggested that we use the National Health Council's time sheets, which we have implemented—it is for this reason; because when you estimate, you estimate.

Senator MONDALE. Was General Shannon's salary included in the 1972 amounts?

Mr. SMITH. I do not know, sir.

Senator MONDALE. Is not Shannon in fundraising?

Mr. FUNK. No sir. He is the head of the Administration and Finance department.

Senator MONDALE. He does not do anything about fund raising?

Mr. FUNK. In that connection, yes, he would have some interfaces with fund raising.

Senator MONDALE. In 1973 you allocated \$8200 of Shannon's salary for fund raising. In 1972 none of it.

Mr. KATZ. Mr. Funk, is it not true what it is fairly obvious fund-raising salaries had to be understated a little bit for 1972?

Mr. FUNK. No, that is not true.

Mr. KATZ. According to your own figures, either your salary and Mr. Ennis' salary was included or General Shannon's. It is either one or the other.

Going back to what we were talking about before concerning the document prepared in 1972, you estimated that Shannon in 1973 would be spending a third of his time in fund raising.

Mr. FUNK. Correct.

Mr. KATZ. During 1972 you did not have Mr. Rizo or Mr. Sutherland in fund raising, so it stands to reason someone, General Shannon, would have to be spending some time directing fund raising.

Mr. FUNK. I do not know that it stands to reason at all, because our fund raising during that period was primarily direct mail, which could have been handled with four people.

When Mr. Rizzo and Mr. Sutherland were added to that unit, they concentrated on the development of fund raising materials for our chapter. What you just said just does not follow.

Mr. KATZ. Then with the addition of these two extra people what was General Shannon's involvement in fund raising in 1973?

Mr. FUNK. I did not understand what you just said.

Mr. KATZ. After these two people were hired did that mean that General Shannon's involvement in fund raising would increase after these two people were hired?

Mr. FUNK. I would have to look at exactly what he was doing at that time.

General Shannon, who was the head of administration and finance, is in the intensive care unit at Andrews Air Force base.

Mr. Robert Moore, who had been his deputy earlier, and has been helping out currently, has a cardiac condition. This makes it very difficult for Mr. Smith to pinch hit in this area, and I am certain that the subcommittee understands that situation.

Senator MONDALE. I have some more questions, Mr. Funk, about the public health program. I think I am going to submit those to you for the record, and I have some other questions about the drug costs, the cost of working with people who are ill with epilepsy. I would ask you to respond for the record by letter.

Mr. FUNK. Yes.

Senator MONDALE. I am going to ask you to submit any books or notations you have bearing upon allocations for 1972, and I understand that you are authorizing us to write to Price Waterhouse.

Mr. FUNK. I am indeed.

Senator MONDALE. With your authority, we will determine what records they have.

Thank you very much.

Mr. FUNK. Mr. Chairman, there were some other items you requested yesterday.

Senator MONDALE. Very well, proceed.

Mr. FUNK. At yesterday's session I received a sheet listing the names of 57 people purportedly representing a turnover during the

period January 1, 1973, through January 31, 1974, a period of 13 months.

I have checked this list and find that many of these people were not with us in the time frame indicated. We have prepared a corrected list of 43, and in addition to the information items on the list handed us, have added three other items: Positions held at EFA, a column indicating department and supervisor involved, and comments pertaining to what we know about the reasons for leaving, which include:

To get married; going into business; going on to a free lance status; returning to school; poor health; family problems; leaving for more money for better position; and other reasons which were involved in a reduction in force which took place early in 1974.

Two were terminated at the end of our usual probationary period. Two of those listed reported to me, and the remainder reported to one of our six department heads. Where appropriate I have corrected salary figures and other information and have indicated length of tenure.

I am turning this list over to the subcommittee, but would prefer that it not be included in the records of these hearings, for we believe that the information, particularly data pertaining to compensation, is a highly personal matter, and probably does not belong in the public domain.

I would also like to submit a table from the National Health Council setting forth salary ranges based on a survey of members in the \$2 to \$10 million income category, and I would like at this time for the record to verify that all EFA salaries, including my total compensation, are within those boundaries.

Senator MONDALE. What is that a study of, comparable salary figures?

Mr. FUNK. Yes, with one exception: we pay our director of program services \$42 more, and we think he is worth it.

Yesterday I was handed a sheet developed by the subcommittee staff detailing fundraising, and administrative costs, over a period of several years. These figures puzzle us, and we do not know how they were arrived at.

I have taken the sheet and added what I believe to be the correct figures based on four audited annual reports, which I would like to turn over to the committee. These are the figures on the sheet I hold in my hand.

I will endeavor to answer further questions, but if detailed information beyond this is required, I would indeed suggest that perhaps our auditors could provide the same.

Senator MONDALE. We are not going to be interested in looking at them unless you can give us the allocation, and that is the whole question. If you have allocation sheets showing how the money is allocated, we would be interested in going over them and answering your questions, and maybe it would settle some of my concerns, but audits that do not tell us how you allocated the money just beg the question as far as I am concerned.

We will place that in the record.

[The information referred to follows:]

EPILEPSY FOUNDATION OF AFRICA

NATIONAL HEADQUARTERS

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(Brackets = Actuals)

Year	Total Income	Fund-raising Costs	%	General Management	Support
1969	\$2.1 million (\$2,137,797)	\$1,178,405 (\$1,170,405)	57% (55.1%)	\$211,000 (\$210,000)	67% (64.9%)
1970	\$2,383,000 (\$2,471,131)	\$1,143,737 ()	48% (46.3%)	\$232,545 (\$232,045)	60% (55.7%)
1971	\$2,700,000 (\$2,773,330)	\$1,155,000 (\$1,155,036)	44% (41.8%)	\$332,000 (\$331,210)	55% (53.6%)
1972	\$3,200,000 (\$3,226,322)	\$1,274,000 (\$1,274,171)	40% (39.4%)	\$362,000 (\$362,163)	50% (50.7%)
1973	\$3,500,000 (\$3,670,763)	\$1,460,500 (\$1,408,501)	42% (38.4%)	\$378,000 (\$423,066)	51% (47.89%)

(1) In 1971 and 1972, EFA reported chapter income and expenditures. In 1971, chapters raised about \$700,000, and spent \$70,000 on fund-raising, \$175,000 on general management and the rest on programs. In 1972, \$300,000 was raised, \$90,000 spent on fund-raising, \$300,000 on general management and the rest on programs.

(2) Non-direct-mail income = \$100,000 in 1971, \$300,000 in 1972 and \$166,000 in 1973.

Combined:

1969					
1970					
1971	(\$3,376,833)	(\$1,210,521)	(36.1%)	(\$507,380)	(51.1%)
1972	(\$4,147,162)	(\$1,365,107)	(32.9%)	(\$511,797)	(47.6%)
1973	(\$5,216,278)	(\$1,508,800)	(28.9%)	(\$720,743)	(52.7%)

*Submitted by EFA

PERSONNEL SALARY RANGES

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Based on National Health Council Member Survey
 (\$2-10,000,000 Income to National Office Category)

<u>Title</u>	<u>Salary Ranges</u>	<u>EFA</u>
Chief Executive	\$31,500 - \$60,000	\$44,500
Deputy Executive*	20,000 - 40,000	30,645
Chief Executive For Financial Affairs	18,000 - 34,500	27,954
Chief Executive For Training	14,000 - 24,400	24,000
Chief Executive For Fund Raising	12,000 - 35,500	22,487**
Chief Executive For Program Services	30,000 - 31,500	31,542
Chief Executive For Field Services/ Community Development	12,000 - 40,600	25,263
Chief Executive for Public Information and Education	16,000 - 31,500	16,395***
Chief Executive for Materials Development	27,000 - 28,500	16,395***
Chief Executive for Legislative Relations	24,000 - 25,000	16,792****
Medical Director	24,000 - 40,600	Volunteer
Research Director	23,000 - 40,000	17,709
Professional Education Director	17,000 (1 only)	17,709

NOTE: Comparisons are difficult because of the varied combinations of functions actually used and reported by member agencies. Other surveys and data used by EFA in these areas include U.S. Civil Service Grade-Step Scales, American Society of Association Executives materials and non-profit organizations surveys done by various management consultants.

* Meaning the Executive Director. See other materials for ranking of and data on Associate Executive Directors.

** Meaning the Deputy Director. The Executive Director personally heads this function.

*** Meaning the Deputy Director. The Chief Executive Officer personally heads this function.

**** Meaning the Manager of the Combined Government Affairs Office. Dr. Perlman personally heads this function.

Senator MONDALE. Has Price Waterhouse been your auditor all along?

Mr. FUNK. I believe for 4 years, Senator. Certainly they have been for the four annual reports that I referred to. We believe them to be the best in the field.

Senator MONDALE. Very well. Thank you very much.

Our witnesses consist of a panel of medical experts: Dr. John F. Kurtzke, professor of neurology of Georgetown University, and Dr. Donald Harting, former director of the National Institute of Child Health and Human Development.

STATEMENT OF JOHN F. KURTZKE, M.D., PROFESSOR OF NEUROLOGY, GEORGETOWN UNIVERSITY, WASHINGTON, D.C., ACCOMPANIED BY DONALD HARTING, M.D., FORMER DIRECTOR, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

Dr. KURTZKE. Mr. Chairman, I am Dr. John F. Kurtzke; and I would like to offer the following as a joint statement of myself and Dr. Leonard T. Kurland, who regrets his inability to be present. Dr. Kurland received his MD from the University of Maryland, M.Ph. from Harvard, and D.Ph. from Johns Hopkins.

He was also trained in clinical neurology, and was formerly the chief of the epidemiology branch in what was then NINDB. He is professor and chairman of the Department of Epidemiology and Medical Statistics at the Mayo Clinic and Medical School.

He is a member of the prestige societies of both neurology and epidemiology: the American Neurological Association and the American Epidemiological Society, the latter of which he is in fact now the president.

I received my M.D. from Cornell and am board-certified in neurology. I am professor of neurology and professor of community medicine and international health at Georgetown University School of Medicine.

I am also consultant in neurology to the National Navy Medical Center and to the Surgeon General of the Navy, as well as chief of the neurology service of the VA Hospital in Washington. Like Dr. Kurland, with whom I have collaborated since 1956, I too am a member of both the American Neurological Association and the American Epidemiological Society.

The statement we have to offer deals with the available evidence as to the frequency of epilepsy. The data presented may be found in chapter 48 of Baker & Baker's "Clinical Neurology" (Harper and Row 1973) which is entitled: "The Epidemiology of Neurologic Disease" by myself and Dr. Kurland.

The epilepsy data therein are in turn based upon our chapter 2 entitled: "Convulsive Disorders" in the APHA vital and health statistics monograph entitled: "Epidemiology of neurologic and Sense Organ Disorders" by Kurland, Kurtzke and Goldberg (Harvard Univ. Press 1973).

Additional material may be found in NINDS Monograph No. 14 "The Epidemiology of Epilepsy; A Workshop" (DHEW Publ. No. (NIH) 73-390, 1972). I have included with this statement one page from the Baker chapter and several from the monograph.

[The material referred to follows:]

Dr. KURTZKE. To begin though, some definitions are in order. "Epilepsy" is not a single disease but a group of disorders which may be secondary to cerebral lesions of varied cause, or may occur without demonstrable brain pathology. The manifestations vary from generalized tonic-clonic convulsions to minor lapses of awareness.

Also seen are seizures only affecting one part of the body or only altering mental behavior. The nomenclature of the types of seizures is still not settled, but in general neither single seizures nor febrile seizures of infancy are considered "epilepsy."

Frequency of disease is best defined by relating the number of cases of the illness to the population from which they are drawn. These proportions are then expressed as rates per unit of population.

The incidence rate refers to the number of new cases of illness per unit population beginning in a stated time interval. We shall see that the annual incidence rate for convulsive disorders is about 40 per 100,000 population, which means that each year there are some 80,000 new cases in the U.S. population of 200 million.

The prevalence rate of a disease is the number of cases present at one time within a defined population, again expressed as a suitable proportion. Thus 500 cases per 100,000 population can be cited as 5 per 1,000 or 0.5 percent as well as 1 million per 200 million. The date on which the cases are counted is called the prevalence day.

Both of these rates can also be limited to a specific age-group, sex, or race. In these instances both the numerator (cases) and the denominator (population) refer to the same segment of the general population. Thus the age-specific annual incidence rate for epilepsy is maximal in the 0-9-year-age group as seen in the figure 48-15 of Baker chapter.

The page (20) from the Baker chapter provides a summary of the best estimates we have as to prevalence and incidence of epilepsy. Further detail, as well as descriptions of the studies from which these rates were drawn, is provided by the monograph pages 24-33 which are appended.

From table 48-9 of Baker, it is clear that most of the prevalence rates recorded are about 4 to 6 per 1,000 population. Three of the four highest include "inactive" seizure patients—that is, those not on medication and without seizures for a specified interval before the prevalence date.

Accordingly we have taken a prevalence rate of about 5 per 1,000 as a reasonable estimate of "active" seizure disorders. This would mean there would be approximately 1 million persons who can be identified as epileptic at any given time in the United States.

Age specific prevalence rates do not show much consistency among the major studies as seen in table 2.4 of monograph. Four of the five studies show declining rates after about age 40, but the recent survey from Rochester, Minn., has increasing rates with increasing age. There are no data of which I am aware that provide any appreciably higher prevalence rates than those listed in the cited tables.

If there are any questions I would be pleased to try to answer them.

Senator MONDALE. It might be well if we hear from Dr. Harting and reserve questions following his testimony.

Dr. HARTING. My name is Donald Harting. I am a physician with specialty training in both pediatrics and preventive medicine and public health. I am a retired career officer of the U.S. Public Health Service. My last assignment, prior to my retirement in 1967, was a 5-year period to plan, organize, and subsequently, to direct a new institute at the National Institutes of Health, the National Institute of Child Health and Human Development.

Since then, I served for 5 years as director of a Ford Foundation/American Public Health Association family planning project.

This is my first time, Senator, to be invited to testify as a private citizen. I have been before this body before with both the support and limitations representing an organization; at this time I have neither.

Senator MONDALE. You did a great job. Now you are free and you can tell us the whole truth. [Laughter.]

Dr. HARTING. My purpose in testifying with Drs. Kurtzke and Kurland today is to emphasize the need for scientific skills in any procedure to evaluate the activities of voluntary health agencies serving children.

If the public is to fully informed, I would hope that whatever mechanism the Congress might establish to protect the public's interest would include the capability for technical evaluation of information produced or activities carried out by such agencies.

Mr. Funk emphasized yesterday that the bulk of the Foundation's resources are used to pay for information activity, particularly publications. For a number of years, beginning in the 1950s when I served as regional medical director for the Children's Bureau in Chicago, I have been concerned with the provision of health services for handicapped children, including those with epilepsy.

Last summer, when I was considering the possibility of working in the field of epilepsy, I talked with Mr. Funk and Mr. Ennis about my possibly providing some technical staff help to their organization.

In the course of this, I reviewed some of their materials to see the type and quality of work being done and frankly the kind of organization with which I might be professionally associated.

I would like to select five examples of different kinds of EFA documents that bothered me then, and still do today.

First I would like to turn to this document which is entitled "Epilepsy is America's Concern", a copy of which you have reproduced in front of you in this form (indicating).

Senator MONDALE. Yes, that will appear in the record as a part of the discussion.

[The information referred to follows:]

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For the Four Million

A gift to the Epilepsy Foundation of America will help bring hope to the four million Americans who have convulsive disorders. Although there are many ways to contribute to the programs of the Foundation and its chapters, a particularly lasting and thoughtful method is through the use of legacies and bequests. Individuals who wish to name the Foundation as a beneficiary may use the following form:

Bequest to the Epilepsy Foundation of America

"I give and bequeath to Epilepsy Foundation of America, a not-for-profit corporation organized for the purpose of research, education, and service in the field of epilepsy, and having its principal office at Suite 1116, 733 - 15th Street, Northwest, Washington, D. C. 20005, the sum of \$ _____ for the general purposes of such corporation."

Bequest to the Epilepsy Foundation of America

The Foundation also encourages funds to be bequeathed for specific program purposes. Additional information concerning bequests, memorials, and other forms of giving can be obtained by writing to EFA's National Headquarters. With recent and proposed changes in the tax structure, it is advisable that you also consult an attorney in your area on such matters.

Note: The little girl on the cover is eight-year-old Dawn Martin, of West Palm Beach, Florida, who has had epilepsy since infancy.



Epilepsy

FOUNDATION OF AMERICA

733 15th STREET, N.W. • WASHINGTON, D. C. 20005

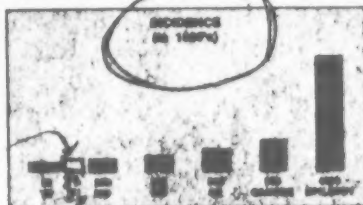
EPILEPSY IS
AMERICA'S
CONCERN

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Epilepsy is not merely the concern of the epileptic, or his doctor. It is not merely the concern of the Epilepsy Foundation of America and the thousands of volunteers who spearhead the attack on this disorder.

It is the concern of every American.

It is America's concern because epilepsy affects more Americans than cancer, tuberculosis, cerebral palsy, muscular dystrophy and multiple sclerosis combined.

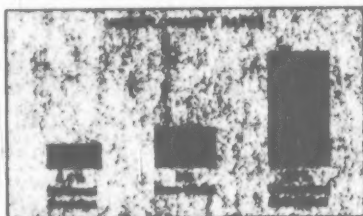


It is America's concern because for every one of the 4,000,000 citizens of this country who have epilepsy, approximately three other Americans are directly affected.

It is America's concern because no one is immune to epilepsy.

It is America's concern because epilepsy costs the taxpayer more than a billion dollars every year in state, local and federal welfare and medical payments.

It is America's concern because no unemployment problem is more severe or more persistent than that of the epilepsy patient. The unemployment rate among just those patients fortunate



enough to have good seizure control—persons who could and should be holding down full-time jobs—is an astonishing 25 percent!

It is America's concern because medically epilepsy is among our most neglected health problems. The National Health Education Committee estimates that fewer than half of the epilepsy patients in this country are receiving adequate medical care.

During 1969, the Epilepsy Foundation of America joined with the American Epilepsy Society, the National Health Education Committee and the Surgeon General's Advisory Committee on the Epilepsies in pointing out these needs:

- Many epilepsy patients must now rely on treatment that has scarcely advanced beyond the age of the bromide. Research into the causes and treatment of epilepsy must be greatly expanded so that all seizures can be brought under control.
- At present there is approximately one highly qualified specialist available to treat every 2,000 epilepsy patients. Support for neurological training in the nation's medical schools must be greatly increased.
- Between 15 and 20 regional centers of excellence in the neurological disorders—clinical facilities parallel to those already established under the Regional Medical Programs for cancer, heart disease and stroke—must be opened if a systematic multi-disciplinary attack on epilepsy and other serious brain disorders is to be carried forth.

Surely, meeting these urgent needs is the concern of every American. And the best way to demonstrate concern is the most direct way—by supporting the objectives and programs of the Epilepsy Foundation of America and its chapters through volunteer work and financial assistance.

Before the formation of the Foundation as the nation's first truly national voluntary organization in the field of epilepsy, there was little the average citizen could do to act on his concern.

Now there is a way.

Dr. KURTZKE. This is not unique. This admixture and confusion is very common throughout medicine at least, but incidence means new cases, and prevalence means how much at one time. It is a big difference in epilepsy.

Senator MONDALE. Where do they get the figures 25 percent of the controlled epileptics are unemployed? Is there data on that?

Dr. KURTZKE. Not that I am aware of.

Dr. HARTING. The only place I know that is given is in the EFA document "The Cost of the Epilepsies" and no reference is given as to where they have obtained that figure.

Shall I proceed?

Senator MONDALE. Yes.

Dr. HARTING. The second item I would like to call to your attention is called the "Data Pak", a factsheet about epilepsy. It looks like this in your folder, sir [indicating].

Senator MONDALE. Yes, we have it.

Dr. HARTING. This Data Pak is a factsheet about epilepsy and the many groups concerned with its medical and social management.

This document states, again, that the primary purpose of the Epilepsy Foundation of America is research. It also exaggerates and uses the 2 percent prevalence rate for epilepsy which would mean 4 million in the United States, but implies that it should be 3 percent or 5 million in the United States. I am most struck, however, by two omissions.

Under the subject of Federal agencies providing resources, lower right hand of the page, it makes no mention of the grants for crippled children's services, historically one of the most important of the Federal and State health programs for children with convulsive disorders.

In addition, on the second page, under voluntary health organizations, no mention is made of the other national organization in this field, the National Epilepsy League, based in Chicago.

For people with epilepsy, this latter group provides antiepileptic drugs at cost throughout the country—last year, about \$350,000 worth.

Senator MONDALE. Are there not some currently good medications and drugs which permit epileptics to carry on in a fairly productive life and prevent seizures?

Dr. HARTING. I would say there definitely are, but I will say Dr. Kurtzke is the clinician in this field and perhaps he should answer that.

Senator MONDALE. I thought there was quite a revolution in this field.

Dr. KURTZKE. There are very good anticonvulsants, foremost of which are Dilantin and phenobarbital.

By and large we are able to control—and this is a clinical guess and not a documented figure between two-thirds and three-quarters of epileptics coming to our attention. Some are exceedingly difficult to control.

Senator MONDALE. But let us say conservatively two-thirds of the persons who have epilepsy can control the problem rather adequately with existing medications?

Dr. HARTING. This leaflet is apparently intended to provide general information about epilepsy and about the foundation as a background for the solicitation of funds. The center part is the information, and the back is information about how to make contributions and bequests. In it at the top of the second page of the material you have there it states:

It is America's concern because epilepsy affects more Americans than cancer, tuberculosis, cerebral palsy, muscular dystrophy and multiple sclerosis combined.

The graph that follows to document this fact is indeed a puzzle.

Whether it reflects a complete lack of technical understanding of statistics on the part of the foundation's staff or is a purposeful distortion of facts I do not know. It is labeled "incidence" you will notice, and does give a figure that is about right for the incidence of newly found cases of tuberculosis in the United States in one year, although incidence charts are usually expressed as Dr. Kurtzke has explained here as the number of new cases occurring in a given period of time, usually a year. That is what incidence means.

However, one gets a clue as to what this really is when one looks at the figure in the column on the right and multiplies the 4,000 by the thousands that it states here, and gets the figure of 4 million.

Now, the clue is that obviously this is the figure that has generally been stated to be the prevalence of epilepsy in the United States, although, as Dr. Kurtzke has indicated, all the studies to date estimate it as about 1 million. But at any rate, they have used in the right hand column the prevalence figure for epilepsy, and in the far left hand column the incidence figure for tuberculosis.

If one were to use to comparable figure for the prevalence of tuberculosis, it would be in the order of magnitude of 350,000 to 600,000, depending on what definition one used.

The other bars on that chart, three of them I am informed by Dr. Kurtzke are pretty close to the claimed prevalence of cerebral palsy, for instance, and the inclusion of cancer in this comparison is of great confusion to me, because it is mixing apples and oranges in many cases.

Some forms of cancer have low prevalence rates: even though they affect a lot of people, because they have a high death rate, and therefore obviously you do not accumulate a lot of cases in a population, but they affect a lot of people.

Other forms of cancer obviously are easily cured, amenable to surgery, and then you can say that you have a high prevalence of previously treated cases of cancer, so how one would include this figure in cancer in here I do not know. I simply say that chart leaves me—

Senator MONDALE. In other words, when they say there are 4 million citizens who have epilepsy, the two of you are testifying that the best data you have show there is about 1 million; is that correct?

Dr. KURTZKE. Yes.

Dr. HARTING. Yes.

Senator MONDALE. But it is your opinion that they play with the difference between what you call incidence rates and prevalence rates?

Dr. KURTZKE. That is a reasonable statement, but that does not prevent them from being labeled epileptics.

One thing that was mentioned yesterday, there is a real stigma against this.

Senator MONDALE. How much does Dilantin cost?

Dr. KURTZKE. Dr. Harting, I think you have figures on that, do you not?

Dr. HARTING. I have the figures from the National Epilepsy League in which they sell it at cost at between 1 and 2 cents for a grain and a half capsule. If one calculates this out, the average epileptic—we were making a calculation yesterday—can buy his drugs through the National Epilepsy League for about \$35 or \$40 a year. On the open market this would probably be at \$70 or something like that.

Dr. KURTZKE. That is using the standard drugs, phenobarbital, et cetera. Others are more expensive.

Senator MONDALE. Let us get into that now. One of the documents prepared by the foundation in a book entitled, "The Cost of the Epilepsies" on page 43 states that the average yearly cost of drugs for an epileptic is \$500.

This is somewhat confusing because in their testimony yesterday they said it was \$100. When you calculate the cost of epilepsy to the Nation the foundation's document multiplies the \$500 estimate of drug cost by their estimate of 3.4 million persons with epilepsy, bringing about a figure of \$1.7 billion.

Dr. HARTING. Senator, I have covered that in my comments as the fifth of my items.

Senator MONDALE. All right, let us wait until we get to that.

Dr. HARTING. We can change the order if you would prefer.

Senator MONDALE. No.

Dr. HARTING. I am simply making a point on this Data Pak that by omitting one of the major groups that does provide services on a national basis to people with epilepsy, it seems to me that these omissions indicate that this information sheet is another promotional document for the Epilepsy Foundation of America rather than a competent and unbiased compilation of useful facts for the person with epilepsy.

The third item I would like to look at is this year's fundraising letter which your committee looked at yesterday, which looks like this [indicating], and starts out: "There is hope for these children," and then underneath it says: "For the estimated 4 million children and adults like them."

As Dr. Kurtzke testified, if the total population with epilepsy is about 1 million, obviously the number of children effected must be well under 1 million.

Again, the emphasis is on research even though only 2.75 percent \$6,806 of 3,157,878 of 1972 expenditures went for research [1972 Annual Report, p. 27]. I have the figures since there seems to be some confusion as to percentage of money going into research.

This fundraising letter reads, "And grants from Epilepsy Foundation of America right now are supporting long-range"—the long

range is my underlining—"research which may finally lead to a cure for epilepsy."

My review of the size and nature of the reported grants made by the foundation coupled with Dr. David Daly's statement of the foundation's research policy yesterday make this statement a highly unlikely one.

As you remember, Dr. Daly stated that the purpose of their grants is to interest new investigators in the field of epilepsy with small fellowships or to make small grants to new investigators for a short period until they can qualify for funds from the National Institutes of Health or other major sources.

This leads to the foundation's techniques of reporting research accomplishments.

Document No. 4, which you have in front of you, is a photostatic copy of the foundation's monthly publication for June 1973, and it is entitled, "EFA Grant Aids Development of 'Dial an EEG' Device"—article from EFA's monthly publication for June 1973.

This article is a report of an important piece of research being done by a team at the University of California at San Diego under Dr. Reginald G. Bickford. The article states that the, "system has been developed under an EFA grant" and makes no mention of other sources of support.

In the same issue on page 1 specific reference is made to an EFA summer fellowship to Robert R. Meyers for \$900 to continue his work on this project.

Knowing that this type of research is expensive, I looked up the NIH research grants to Dr. Bickford. I found that in addition to other NIH grants, he has been the recipient of \$394,261 over the last 4 years to study, "Automatic Pattern Recognition of EEGs" [No. 5R-01-NS-08962].

Although EFA may have made additional small contributions to this major and worthwhile investigative effort, the public is hardly being accurately informed when no mention is made of the primary source of support.

Senator MONDALE. This system has been developed under an EFA grant—would not an uninformed reader assume that—

Dr. HARTING [continuing]. That EFA was paying the primary cost of the research. That would be the assumption, except that it happens that NIH has during the same period made four grants totaling \$394,261 to the same investigator for the same general area of work while the EFA is announcing its contribution of \$900.

Senator MONDALE. And that is not mentioned in this article at all.

Dr. HARTING. No, it is not.

Last, I turn to the document that you have in your hand, "The Cost of the Epilepsies"—a report published in 1974. This document was released at the time of the introduction of SJR-173, and, judging by the statements in the Spokesman, the foundation's literature, was to provide evidence as to the need for such legislation.

My concern is that a document such as this could do more harm than good to the field of epilepsy if it is accepted as having any scientific merit. The foreword states that, "In this particular study, however, the aim of the EFA in assembling data has been to utilize only those figures readily verifiable." That is their underlining.

I have not found the data readily verifiable, nor even verifiable with some effort. It appears to be a collection of the highest figures available from any quotable source without any discrimination as to the likely reliability of the source.

Such exaggerations can potentially do great harm to the cause of epilepsy if accepted as having validity and used for other purposes, for example, to justify exclusion from insurance programs or to justify lesser Federal support for drug development.

I shall examine, in the interest of time, just one example, the basis for one item—private medical costs—that accounts for \$1.7 billion or 40 percent of the total cost. It is arrived at basically by multiplying two simple numbers:

3.4 million people with epilepsy—this is the foundation's 2 percent prevalence rate of 4 million minus the 600,000 people already accounted for in other sections of the report. There is no attempt to subdivide these 3.4 million persons with epilepsy as to whether they need care now, have care available, could pay for it if they had it, and so forth. This cannot be done, in fact, since the 2 percent estimate is not based on any data and therefore provides no basis for subdivision.

This is then multiplied by the figure \$500, the estimated average amount now being spent by every person with epilepsy. The reference given for this figure is to an information document published by the National Institutes of Health. I am sorry I did not provide this for you but I have it here for you. This document simply states by footnote, if you look at the bottom right hand page, partially disabled individual, \$500, for drugs, physician's fees and special management. This footnote is the figure used for estimating the annual cost of care for individuals partially disabled from a whole array of serious neurological disorders, not epilepsy alone, you will see by looking over on the left. This leaflet is the reference to which this document—"The Cost of the Epilepsies"—makes reference in using the \$500 figure.

The reason no data are given is that it was a guess made one afternoon by two writers on the information staff in consultation with a neurologist and a neurosurgeon.

I would not like to use the names because the physicians involved had no idea what they were being asked by two information people to give a guess on a figure that would ever be used in this fashion, and therefore I think their names should be protected.

Dr. KURTZKE. It is not mine though. [Laughter.]

Dr. HARTING. I have pointed out the degree to which I have been able to readily verify the facts used in obtaining this \$1.7 billion figure. I would point out some dangers however, for if the resulting figure for private medical cost had any basis in fact it would mean:

(1) That any insurance carrier or health maintenance organization intending to insure a general population would have to charge significantly more than \$10 per person per year just for the care of those having epilepsy in the population.

I say it would be more than \$10 because if EFA claims \$10 is now being spent, any insurer knows that the rate goes up significantly if

one provides insurance, because of the increased utilization over present costs.

I do not have the figures, but I cannot imagine that this is even in the ball park of the experience of any insurance carrier.

(2) That the present expenditure for antiepileptic drugs is about \$170 million, since the cost of drugs alone is about 10 percent of the cost of treatment for epilepsy.

If you will note page 42, in note 2, in this EFA document, it points out that the sales of \$77 million reported by the U.S. Tariff Commission in 1970 is a gross underestimate, since the report lists only drugs manufactured by at least three companies. Now, this is typical of trying to get as inflated a figure as one can because no attempt is made to delete the fact that phenobarbital, for instance, and some of the other drugs are used for other purposes than epilepsy, so if one were to put the ball park that one would get from this document as to the current moneys being spent on antiepileptic drugs, it would be some place between \$80 and \$180 million.

These figures would be very inappropriate and detrimental to have in the literature, since a major justification for Federal subsidy to the National Institutes of Health's present drug development program is the limited potential market for new antiepileptic drugs in relation to their cost of development.

It seems to me that Congress is wisely acting at this point in supporting a program at NIH to develop and subsidize the development of drugs in this field. I would think that anyone who was anxious to save money could well point to this document, and point to the large market that it says there is because of the costs at the present time being someplace in the hundreds of millions of dollars.

This is simply not even in the ball park of any of the estimates that I have seen used in justifying NIH's current research program, and I think Congress is wisely responding by putting in money to subsidize the development of drugs for epileptics.

Senator MONDALE. Dr. Harting, you said at one point that you talked with Mr. Funk about perhaps being a consultant or working with EFA; is that correct?

Dr. HARTING. Yes, I did.

Senator MONDALE. In the process of that you reviewed some of their public information materials.

Dr. HARTING. Yes. Actually Mr. Funk gave me a draft copy of this study on the cost of the epilepsies, so that I could see the kind of thing that they were working on.

Senator MONDALE. Did you tell Mr. Funk which you thought of that literature?

Dr. HARTING. I am a afraid I did.

Senator MONDALE. What did he say?

Dr. HARTING. I told members of his staff—I was not actually able to get back to Mr. Funk; he seemed to be busy with other things—that I had serious reservations about the value to the field of epilepsy of this document, if it would get into print in the form that it was in, and that I saw a need for technical help within the organization in terms of EFA's apparent difficulty in producing accurate technical information.

At that time I was willing to see it clearly as a problem of a voluntary organization, being able to get technical people to work for them at reasonable cost.

I offered to help within whatever limits they had on funds available, and whatever consultative time they might want—and a no-risk kind of arrangement; I did not want any long-range commitments either at the time—the thing I did ask for was that I would be assured the intent of the organization was to clean up this kind of material, and that I would have access to the senior parts of the administration in any work that I would do.

I have not heard from them subsequently. I can quite understand that they might well prefer to try to find someone who is more competent or easier to get along with than I.

Senator MONDALE. That document I think was later released, was it not? This is the one [indicating]: "The Cost of the Epilepsies"?

Dr. HARTING. Yes. I had been assured that would be reviewed for accuracy by their professional advisory board; that that could not possibly get into print the way it was. I was absolutely taken back when I saw that it had been introduced as evidence for the foundation's being given the leadership role that is called for in Senate joint resolution 1973.

Senator MONDALE. Dr. Kurtzke, others have offered to testify, and we will try to handle as many as we can—or perhaps it was Dr. Harting who indicated in your statement the technical evaluation carried out by such agencies. I think we all want to maintain—at least most of us do—a very flexible private voluntary sector. I feel strongly about that.

Dr. HARTING. And I would agree.

Senator MONDALE. As you know from your government experience, there are certain inhibitions and delays, and this and that, and even some kinds of risk in some kinds of research of a political nature that make the private voluntary sector an important part of our health picture.

I would certainly hate to be in a position where we would establish some sort of government czar who must approve and pass upon and establish a public standard.

I do not think you could pass it if you wanted to, and I think it would be a bad idea if it did.

Yet you have this kind of testimony about many aspects of a very large charity raising over \$4 million a year, people giving a lot of their money, hoping to help epileptics, and one wonders about the accuracy of the statement made in the course of raising that money, the public information service, and the rest.

That raises the question about what about the quality of research? Maybe it is just fine, but how does the public have any way of knowing?

We had testimony here a few months ago by the Asthmatic Foundation, whose nonprogram service ran about 90 percent of costs, and they were raising over \$1 million a year, and they helped care for 50 or fewer asthmatic children when they were severely stricken—that is true and that was their theory of delivery of service—but of

course if you divide \$1 million into 50, that is a pretty expensive program.

Should there be some system for commenting on the quality of these services? You know the Securities and Exchange Commission does not pass judgment on the basis of stock but it says the prospectus has to be honest, there has to be full disclosure.

How do we deal with this?

Dr. KURTZKE. The problem is multiple here. One is that data on frequency of diseases are not that common; they are not that well known, and many excellent specialists in neurology or other areas do not have these numbers available and do not know where to find them.

The book I am citing, for example, is in fact the first one ever to come out as a book listing at least most of the major neurological diseases in terms of incidence, prevalence, mortality rates, so there is a basis for past misunderstanding.

Since this came out I have had inquiries from other voluntary agencies too commenting in essence: How come your numbers are so much lower than what we are using?

All I do is xerox the part of the book in question, and send it back to them; but I never hear any more.

Incidentally if the chairman would like to borrow this, feel free. There is information other than on epilepsy in it.

Senator MONDALE. I will read it tonight.

Dr. KURTZKE. So one thing is lack of information in the past.

Another is my own feeling that the voluntary agencies are making a big mistake thinking they are selling toothpaste. The big numbers turn people off after a while.

If you see on television 1 million affected—one time an epidemiologist from Harvard presented a paper postulating that by taking voluntary agency claims, every individual in the country was affected with at least two diseases. [Laughter.]

So I think it is a mistake, a tactical mistake, on the part of the fundraising agencies to use inflated figures.

Senator MONDALE. It is amazing how fundraising costs are always de-emphasized but the nature of the disease is exaggerated. Why would that be?

Dr. KURTZKE. I have no answer for that.

Senator MONDALE. I think there is a very serious policy question here when we get into the quality of the program that goes beyond bookkeeping, that goes beyond candid disclosure of fund raising costs, overhead problems, management problems, and the rest.

I wonder if there is not some way of at least getting an outside look at this. I hope the National Health Council witness will comment on this when he testifies.

Dr. KURTZKE. I am sure you could get excellent expert neurologists to testify that there are many more epileptics around than we count or have been able to count, but the basis for that is impression. There are no data that I am aware of that show any appreciable higher rates. If one says there could be more, this cannot be negated.

Senator MONDALE. That is an opinion of people with experience.

Dr. HARTING. Senator, I must say that my interest has not just been in the Epilepsy Foundation, but as I got into this question I became very much concerned with the specific question that you are concerned with.

When I found that to all practical purposes there would be no practical control on going into business and starting a foundation in this field as far as I could see. I was struck by the fact that there is nothing comparable to the Securities and Exchange Commission where one is raising funds throughout the country the same way one would do if one were floating a new debenture.

Senator MONDALE. And it is tax exempt to boot.

Dr. HARTING. That is true. The Securities and Exchange Commission clearly does not pass on all of the virtues or lack of virtues of an investment. It does have technical staff though for the issues on which it is assuring the public.

When I say that it seems to me important to have technical staff involved in the process of looking at the policies, procedures, fund raising methods, the kinds of data being put out, it seems to me that it would be very easy to fool a bookkeeper in terms of what was research and what was not research.

It seems it would be very easy to fool people in terms that the information to all practical purposes in fraudulent, if one does not have the knowledge of where to go or where to find resources against which to check data.

Therefore it seems to me there is some need for technical input. Having just gotten out of government, I have exactly the same worry that you have, and this is the reason I was looking at private foundations.

I have been terribly much upset by the current administration's doing away with any focus on professional knowledge about disease processes affecting children. I am sure you have heard of the fact the staff of the children's bureau—you cannot find them any more; there are no technical staffs in government who know about and can be doing any kind of sensible program planning for specific problems.

In medicine we do not make progress just by getting more hospital beds available. We make progress by defining a disease, defining ways of getting at it and taking action.

The present Government structure is terribly weak in this, and yet it was my dissolution with it, as I looked into the voluntary field that brings me here today. But I thoroughly agree that the freedom of action cannot be hampered.

I have concerns about which I will be quite frank. The American Medical Association did a listing, for instance, for a while back, but it did not have the nerve to make any judgments that might help people.

The National Health Council has for years had this responsibility, but to my knowledge has not exercised it. If you look at the method by which it is funded, it is funded by contributions from its member agencies, it would be biting the hand that feeds it obviously to make any critical judgments.

I would wonder if some organization such as the Academy of Pediatrics, which has a good reputation for having done public service going back to the 1950's when they did a national survey of methods of providing service for children in this country by general practitioners and others—I wonder, if, for instance, a private group such as the Academy were encouraged to set up a committee that might provide input at least, and might be funded to do so.

There is another national organization that has recently been formed, the Council of National Organizations for Children and Youth, a follow up to the old National Committee for Children and Youth.

It has avoided having public funding, so it would be free to provide technical information, and does have good health people associated in various ways with it. I think there are a number of mechanisms. My only plea is that the public needs more than simply the bookkeeping facts.

Senator MONDALE. Of course this whole problem of charities goes much further. It affects the children who cannot protect themselves. It affects the contributor who really does not have much to say about it once the money is given. There is no one to check out the candor of the disclosures of fund raising costs, the quality of the program. It can be a pretty free floating operation.

Dr. HARTING. I agree.

Senator MONDALE. Thank you very much for your most useful statements.

Our next witness is Frank Self, executive director, Greater New York Chapter, Epilepsy Foundation of America.

If you will proceed, Mr. Self.

**STATEMENT OF FRANK SELF, EXECUTIVE DIRECTOR, GREATER
NEW YORK CHAPTER, EPILEPSY FOUNDATION OF AMERICA**

Mr. SELF. Mr. Chairman, I have a statement which I have submitted which I would like to read because it tells very briefly what the Greater New York Chapter of the Epilepsy Foundation of America has been doing.

First, I would like to point out to the chairman that I served as executive director for the Texas Administration for Mental Health and as director of public relations and fund raising for the National Association of Mental Health, and in a similar position for the National Cystic Fibrosis Foundation. There I am somewhat familiar with the issues of the National Health Agencies with which you are concerned.

The Greater New York Chapter, Epilepsy Foundation of America, is a not-for-profit voluntary health agency incorporated in the State of New York, and franchised by the Epilepsy Foundation of America, Inc., to carry on a program of client services and public education within the five boroughs of Greater New York City. Administrative and fund raising policies are determined by an elected board of directors, presently constituting 17 in number. Program policy and its implementation are determined by an elected professional advisory board, presently constituting 20 in number. Elected

officers of the board of directors are a president, vice president and treasurer, vice president and secretary, and two vice presidents, who also constitute the executive committee.

The Greater New York Chapter, EFA, has a paid staff of 13 full and part-time employees consisting of an executive director, program director, director of mental health services (M.D.), staff psychologist (Ph.D.), rehabilitation coordinator, director of community education, three social workers, counselor-evaluator, coordinator of administration and fund raising, and two program secretaries. In addition, the voluntary (unpaid) services of five university graduate students in rehabilitation counseling and two university undergraduate students in social work are utilized in initial client interviewing and in group counseling.

Our chapter offers free client services to persons with epilepsy and their families in social work, psychiatry, psychology, rehabilitation, vocation evaluation and counseling, and job placement, as well as providing appropriate advocacy services. A daily morning workshop is conducted to assist severely afflicted epileptics in developing basic adjustment skills. Supervised group therapy and social sessions are conducted each Saturday, and family counseling sessions are held weekly. A continuing community education program is carried on throughout Greater New York involving schools, police, professional, and lay groups, as well as media contact and coordination and dispensing literature and information. A Preschool Outreach program is conducted in collaboration with community outreach teams of New York Medical College, designed to seek out and refer to medical care the very young seizure victims of Harlem and East Harlem ghetto areas, who often go untreated until their entry into the public school system.

Professional relationships are maintained with other health service agencies, New York Board of Education, mayor's office for the handicapped, operation headstart, American Pediatrics Association, and other agencies.

During 1973, our chapter provided direct professional services to 306 clients, as well as individual services of 773 professionals and 3,301 clients. Chapter personnel participated in 84 public and professional meetings involving community education, and took part in 17 public exhibits and educational displays. Chapter personnel took part in 37 professional and program meetings.

The greater New York chapter EFA, is funded by two development disabilities grants administered by the Department of Mental Hygiene, one grant from the National Institute of Health in Washington, and voluntary citizen contributions solicited from the public at large in the greater New York community. During the fiscal year 1973, the chapter received \$10,000 in subsidy grants from the Epilepsy Foundation of America, Inc., in Washington, D.C., and \$14,000 in non-interest-bearing loans from EFA. Total chapter income for the fiscal year 1973 amounted to \$182,706, with expenditures for the year of \$174,329. Fund raising costs for the year amounted to \$16,879, or 9.6 percent of expenditures. Fund raising mailings are made to established donors—house list—and purchased and loaned lists of voluntary contributors within the greater New

York City area. Appeals are made to local foundations, corporate donors and philanthropic resources. A limited program of special events and memorial tributes is carried out.

Current—1974—fund raising plans include target mailings to purchased lists of donors specifically interested in rehabilitation and education for the handicapped, services to children, and general health services. Two major special events have been scheduled for the present year. An expanded memorial tributes and bequests program has been undertaken. Continuing efforts are being made to increase the size of the present board of directors through recruitment of community and civic leadership capable of and interested in strengthening the voluntary fund raising programs of the chapter.

Steps have been initiated to convert the chapter's existing workshop to full licensed sheltered workshop status, which will enable the chapter to provide more sophisticated and effective vocational training and allow the chapter to qualify for certain private and governmental contract work.

The greater New York chapter, EFA, is currently in the process of merging with the 16-year-old nonaffiliated United Epilepsy Association of Brooklyn, which, upon the filing of appropriate certificates of dissolution with the attorney general and secretary of state of New York, will bring capital assets and additional inventory of office machinery and equipment into the organization. The chapter will continue operation of the Brooklyn facility as a branch—satellite—office. A branch office is also maintained for information and referral service in the Richmond Mental Health Center on Staten Island, staffed by volunteers.

In addition, we have a complete financial statement.

Senator MONDALE. That will appear in the record as read.

[The statement referred to follows:]

STATEMENT OF THE GREATER NEW YORK CHAPTER, EPILEPSY
FOUNDATION OF AMERICA, PRESENTED BY FRANK B. SELF, EXECUTIVE DIRECTOR

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The Greater New York Chapter, E.F.A., has a paid staff of thirteen full and part-time employees consisting of an Executive Director, Program Director, Director of Mental Health Services (M.D.), Staff Psychologist (Ph.D.), Rehabilitation Coordinator, Director of Community Education, three Social Workers, Counselor-evaluator, Coordinator of Administration & Fund Raising, and two (2) Program Secretaries. In addition, the voluntary (unpaid) services of five university graduate students in Rehabilitation Counseling and two university undergraduate students in Social Work are utilized in initial client interviewing and in group counseling.

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severely afflicted epileptics in developing basic adjustment skills. Supervised group therapy and social sessions are conducted each Saturday, and family counseling sessions are held weekly. A continuing Community Education program is carried on throughout Greater New York involving schools, police, professional and lay groups, as well as media contact and coordination and dispensing literature and information. A Preschool Outreach program is conducted in collaboration with community outreach teams of New York Medical College, designed to seek out and refer to medical care the very young seizure victims of Harlem and East Harlem ghetto areas, who often go untreated until their entry into the public school system.

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Senator MONDALE. Now, I would like to answer certain questions that we asked you to testify to today.

Would you state briefly what kinds of services your chapter provides to people with epilepsy.

Mr. SELF. We provide, as I said, the full range of service. We have paid professional staff who provide free services and counseling.

Our primary emphasis, because of the need of the clientele we serve, is in the area of mental health. It is in the area of support.

There is a great deal of psychological burden attached to suffering

from epilepsy. It relates all the way back to childhood and continues and is particularly difficult with teenagers.

Senator MONDALE. Where do you get your money?

Mr. SELF. Primarily through government grants.

Senator MONDALE. Is that Federal?

Mr. SELF. They are development disability grants administered by the New York State Department of Mental Hygiene.

Senator MONDALE. What is your annual budget, approximately?

Mr. SELF. \$200,000 for the current year.

Senator MONDALE. You get all that from Federal grants?

Mr. SELF. No. Last year we received approximately \$100,000 or a little more from Federal funding. You see the DDSA grants are matching grants. We get \$0.70 and we have to raise \$0.30 to match it.

Senator MONDALE. Where do you get the \$0.30?

Mr. SELF. By mail solicitation and by special gift campaigns and various fundraising activities.

Senator MONDALE. You handle those yourself at the local level?

Mr. SELF. Yes.

Senator MONDALE. What do your costs fundraising run?

Mr. SELF. 9.3 percent.

Senator MONDALE. We have been told that epilepsy is so odious in the minds of many Americans that fundraising costs are inevitably higher, yet you are able to raise your money at about the rate of 9.2 percent.

Mr. SELF. I am able to do that, sir, because both the National EFA and our local chapter are very poor. I think these figures may be misleading because I operate without a secretary, without any campaign staff assistants. It is a one-man operation.

Senator MONDALE. But this keep the costs down. Do you mail?

Mr. SELF. Yes, we do mailings. We do mailings to our established donors in the New York Community, and then we do target mailings to purchased lists.

Senator MONDALE. Does the National headquarters solicit money from people in your community?

Mr. SELF. Yes, sir.

Senator MONDALE. That is by direct mail?

Mr. SELF. Yes, sir.

Senator MONDALE. Do you have any knowledge of how much it raises in New York?

Mr. SELF. No, sir, I have no way of knowing.

Senator MONDALE. Have they ever been asked?

Mr. SELF. No, but members of my Board of Directors have asked.

Senator MONDALE. What kind of answer do they get?

Mr. SELF. They were shown certain figures prior to my joining the staff which indicate the amount of money coming in from the Greater New York Community was in the neighborhood of \$100,000 to \$125,000.

Senator MONDALE. How much money do you get back from National headquarters?

Mr. SELF. Last year we were given \$10,000 in subsidy grants and \$14,000 in loans. This year we no longer receive subsidy.

Senator MONDALE. Do you have a loan?

Mr. SELF. There were loans in 1973 to enable us to meet our matching commitments.

Senator MONDALE. You have a \$10,000 grant?

Mr. SELF. We received \$2,000 per month for 5 months.

Senator MONDALE. Was that for general operations?

Mr. SELF. That was primarily for the matching purposes.

Senator MONDALE. What other kinds of assistance do you receive from National headquarters?

Mr. SELF. We are different, Senator, in that our chapter does not require a lot of assistance from EFA. I might point out, EFA has over 160 chapters, and they vary widely in the level of sophistication, in the level of volunteer activity.

Our chapter has a full professional staff, and we have at least one person who is devoting time to fundraising, with I might say some considerable experience in fundraising, through other health agencies; therefore, we do not require a great deal of national assistance.

Senator MONDALE. Does the fact that the National Epilepsy Foundation solicits in New York make your fundraising more difficult?

Mr. SELF. Yes, sir. I recognize that the National EFA has to have money. At the present time their only major source of income is by mail.

In ideal terms, it would be much simpler to raise money in New York if National EFA did not raise money simultaneously. It would also be less confusing to the public.

But we are up against a problem of not having any alternatives. I support a national concept, and I would hate to see the National Epilepsy Foundation of America cut off from its present source of income, although it frankly does create a problem in New York, because we have duplicate mailings which go to people and just confuse the public. This is a problem we have discussed. We are aware of it.

Senator MONDALE. Thank you very much, Mr. Self.

Our next witnesses consist of a panel representing State regulatory agencies: Carol Cochran, director, Commission on Charitable Solicitations, of Harrisburg, Pa., and Ed Edgerton, chief, Solicitation Licensing Section, Department of Human Resources, Raleigh, N.C.

We are very pleased to have you. Would you proceed with your statements, please.

We will include your full statements in the record as though read, and you may proceed as you wish.

STATEMENT OF CAROL COCHRAN, DIRECTOR, COMMISSION ON CHARITABLE SOLICITATIONS, HARRISBURG, PA.; AND ED EDGERTON, CHIEF, SOLICITATION LICENSING SECTION, DEPARTMENT OF HUMAN RESOURCES, RALEIGH, N.C.

Ms. COCHRAN. I am Carol Cochran, director of the commission on charitable organizations for the Commonwealth of Pennsylvania.

The commission on charitable organizations is responsible for en-

forcing Pennsylvania's solicitation of charitable funds act, which requires every charitable organization that intends to solicit or to have funds solicited on its behalf to be registered with and approved by our office annually.

The act charges the commission with the statutory obligation of investigating charities and, where it finds there are violations, or refusing to register a charity or of revoking an existing license.

In 1972 the act was amended and now, among other things, limits how much a charity can spend on all of its fundraising expenses to no more than 35 percent of total public support, and states that no applicant shall be approved if fundraising expenses during any of the 3 preceding years have exceeded 35 percent.

The statute also provides that any applicant who is denied registration may request and receive a hearing before the commission, and that in the event the applicant can present special facts or circumstances showing justification for expenses higher than 35 percent, the commission has the discretion to allow the exception and impose whatever conditions it deems necessary.

Epilepsy Foundation of America first registered with the commission in 1966, and has applied for renewal of registration more or less on an annual basis since then.

On February 5, 1974, we received their renewal application along with a financial report—certified by Price Waterhouse & Co.—based upon fiscal year 1972.

According to the financial report, EFA's total of solicited contributions from the public for the year 1972 was \$3,133,062. Its total solicitation fundraising expenses in raising the \$3,133,062 from the public was \$1,274,171. In other words, its fundraising costs were 40.67 percent of total public support.

Based upon this information, I denied their application for the right to solicit in the Commonwealth and informed the organization of its recourse as provided by the statute.

Epilepsy Foundation of America did request a hearing before the commission, and one was held on March 26, 1974.

At the hearing, EFA offered a second financial report for the same fiscal year, presenting consolidated figures. This, too, showed fundraising costs in excess of our statutory limit.

In this second report, the consolidated report, EFA left blank 180 lines inquiring into the financial status of the organization, including information regarding amounts spent on fundraising for professional fees and services, postage, printing, conferences, salaries, supplies, and so forth. According to EFA the 180 lines were left blank because the information—on a consolidated basis—was not available.

The commission found this second report to be statutorily deficient and therefore not properly before the commission. It then based its decision on the prior application and financial report.

On March 28, 1974, the Commission on Charitable Organizations issued its ruling that Epilepsy Foundation of America's application for registration was disapproved because:

(1) In the 3 years preceding registration, EFA showed fundraising costs in excess of 35 percent;

(2) Testimony presented indicated that expected costs of fund-raising will exceed 35 percent for the coming year;

(3) EFA failed to show that special facts or circumstances existed to allow the organization to circumvent the statutory limit.

Epilepsy Foundation of America has now filed for appeal from the commission's denial, and the case should be before Pennsylvania's Commonwealth Court in the near future.

Mr. EDGERTON. In order to bring my statement to more or less the current situation with the Epilepsy Foundation, I would like to briefly summarize the first page and a half of my statement.

Senator MONDALE. Very well. That is fine.

Mr. EDGERTON. Our experiences began with several epilepsy associations in 1955. From 1955 to 1968, we received 51 mailings into North Carolina, and on a number of occasions we sought cooperation and did receive an application from the Federal Association for Epilepsy in 1962.

The application was denied because of high fundraising costs. Immediately thereafter mailings were resumed.

For a long period of time there were only minimal mailings into North Carolina following the 1968 merger and in response to our appeal for cooperation following a 1970 mail appeal, Mr. Harold Gordon, legal counsel for EFA, submitted an application on their behalf. It was incomplete for failure to receive additional information. Part of the information sought dealt with an 8-point program Mr. Funk had developed to improve the EFA. No action was taken on the incomplete application.

In 1971, a statewide organization was formed in Charlotte, N.C., to assist in programs for epileptics and they were funded by grants for the most part. This organization was first licensed by our office in May 1972 and at that time was a provisional affiliate of EFA.

North Carolina has an administrative policy which provides that if the State unit of a national organization is autonomous, then it is the one to apply for license.

In May 1974, Mr. Don Ostrum, regional representative of EFA was in Charlotte to change the provisional chapter to a full affiliate. I made a statement to him and later conveyed in a letter to an Epilepsy Foundation of America representative in Washington that if EFA were to apply for license after the North Carolina chapter was licensed, then we would withdraw the North Carolina chapter's license and it would be covered by EFA's new license. My statement was based on an erroneous premature assumption that the North Carolina chapter was not an autonomous unit.

EFA did apply for a license in August 1972, some 4 months after being sent forms for applying. This was held in abeyance for additional information and because of the discovery that the North Carolina chapter was autonomous. If action had been taken on the application, in all probability it would have been denied again because of the high fundraising costs or the failure to get only 52 percent of expenditures into program services. In North Carolina we believe that unless an organization gets a minimum of 60 percent into the program services that it should be denied permission to solicit from the citizens of our State.

Even though we have not received a completed application since 1962, we have been furnished by EFA or other sources, audits from 1967-72—except for 1968. From this information it is easy to see some progress has been made in reducing the percent of fundraising costs or inversely a larger percentage going into program services. In 1967 program services amounted to 42.9 percent of total expenditures for the national office and in 1972 they were 48.2 percent.

Mailings have continued into North Carolina by the EFA but not on the scale as before 1970.

Following a February 1974 mailing, I sent Mr. Funk a letter explaining that the North Carolina chapter was an autonomous unit and that EFA should not solicit within North Carolina. We asked for the deletion of North Carolina ZIP codes from mail lists and that we wished to be notified in writing that this was being done. His response explained the problems that EFA faced with my request and they are: (1), chapters are not able to assume as yet their role as the main source of National's income; (2), research grants in North Carolina—about one-tenth of EFA's total—are \$22,000 and approximately what EFA is receiving from the mailing in North Carolina; (3), the EFA's budget and programs would be seriously curtailed without the mailings which raises about \$3 million.

While the question of EFA's mailing into North Carolina remains unresolved at this writing, I have been promised that the EFA executive committee would discuss it in an April 1974 meeting.

If I might be objective for a moment, from our experience, there seems to be only one major problem with EFA in North Carolina, and that is its percentage on fundraising costs. When these are reduced then program service expenditures will take care of itself.

Below are some observations I have made concerning EFA's fundraising problem: (1), there has been a phenomenal chapter growth throughout the Nation from approximately 50 in 1970 to 164 today; (2), if leadership is available for such chapter growth, then it is available to assist these chapters to become a strong and viable source of raising funds and developing programs.

I have received an impression from persons at the chapter level that field people visit, give materials, assistance, and advice to minor problems, but really do not offer the kind of help needed to do a great low-cost fundraising campaign.

(3) Other major health organizations operate for the most part successfully with chapters raising their share also; (4), the stigma that surrounds EFA as a high cost fundraising organization would be removed if chapters were raising a larger share for national; (5), officers and staff in North Carolina prefer no EFA mailing into their area, and I believe most other chapters would agree; (6), the mailings provides competition and confusion within the chapter's geographic area.

In connection with items 4, 5, and 6, I do have a letter from the president of the board of directors from the North Carolina chapter.

Senator MONDALE. We will put that in the record following your remarks.

Mr. EDGERTON. (7), further improvements in reducing fundraising percentages will be difficult if mailings are continued at such a high volume.

One in work such as mine cannot help but raise a suspicious or questionable eye when the EFA steadfastly holds to the mass mailing of letters and would write into merger agreements that mailings must be maintained substantially as before merger.

This organization, epileptics, and the public would best be served if EFA revealed fully all details of fundraising costs and who receives what amount for services performed in fundraisings, also, was this service available competitively or if not, what relationship exists between the organization and the contractor.

Those associated with EFA continue to claim that the "penny letter" is working. Is it working if \$0.42 was spent to raise a dollar while the average health organization spends only about \$0.14-22 to raise a dollar?

Such a statement is akin to the numerous organizations which seem to have adopted the philosophical attitude, "If we net what we want—why worry about the gross, it only comes from the public."

Senator MONDALE. Thank you very much for your statements.

I gather you have a new law in Pennsylvania which limits fundraising costs to 35 percent.

Ms. COCHRAN. That is right.

Senator MONDALE. That is somewhat like the New York law which limits it to 50 percent. It is a similar idea.

On the basis of that new law you have denied the foundation soliciting funds in Pennsylvania.

Ms. COCHRAN. That is correct.

Senator MONDALE. And they have appealed that to the courts?

Ms. COCHRAN. Yes.

Senator MONDALE. What is the basis of their appeal, do you know? Are they arguing against the law or are they arguing the facts, or both?

Ms. COCHRAN. I think they are arguing the nature of our denial, I presume, but we felt that we had no choice but to deny because the current application, as well as the preceding 3 years, looking at the organization all the time that they have been registering in Pennsylvania, since 1966, they have never come close to 35 percent.

Senator MONDALE. Does your office look at the annual documents of a charity to determine how accurately the fundraising costs are allocated?

Ms. COCHRAN. No. We would like to. What we require is a certified report from at least an independent public accountant.

Senator MONDALE. You do not go behind that data and determine whether the allocations reflect all fundraising costs?

Ms. COCHRAN. We could, Senator, but in this particular case when we had a prior history of a fairly consist pattern, certified reports from an outstanding firm, we acted pretty much on the evidence we had before us.

Senator MONDALE. I gather in North Carolina the basis for your action is basically that you have a foundation for epilepsy which is North Carolina based.

Mr. EDGERTON. That is right.

Senator MONDALE. Which is raising money, and you do not want two organizations raising money for the same purpose?

Mr. EDGERTON. Yes. This is right.

They feel that the competition does hurt them, and that it does provide some confusion among the public, having two sources raising funds for the same purpose.

Senator MONDALE. I think that that completes this panel.

Ms. COCHRAN. May I make one comment.

Senator MONDALE. Surely.

Ms. COCHRAN. About the fundraising, we have been kicking about pretty much this organization's expenses, and I would like to make an observation.

I think that any large charity that depends almost totally on direct mail solicitation is going to run into real trouble, not only in Pennsylvania, but with any State that has a fairly tight percentage on fundraising.

What we would like to advocate to the health council or anyone else concerned is a balanced fundraising program.

We believe you have to spend money to raise it, but when you put all your fish in one basket, it is very difficult to meet the statutory limits I think.

Senator MONDALE. Do you accept their argument that epilepsy is sort of a stigmatized disease which inevitably increases the cost of raising money?

Ms. COCHRAN. That would be conjecture on my part. I could speak to the issue that was before the commission.

Our commission was not swayed in its adjudication. The commission has used its discretionary power in the past. A recent example was for a disease which I think was an unpopular disease, leprosy.

This particular organization had a fund raising expense of 53.3 percent, and they acted against their application and denied it.

The organization asked for a hearing before the commission, came in and presented what we felt were extraordinary situations, and they consistently had low fundraising expenses. This was a one-time national mailing that blew their expenses, and they were quite willing to live at less than our 35 percent limit for as long as we asked them to.

So I think we could argue as to what is a popular and what is an unpopular disease, but I believe they are matters of record.

Senator MONDALE. I understand counsel for the national foundation feels that the statement asserted their point of view would be quite relevant, and I hope before the morning is over, we can have a chance to hear that statement.

Thank you very much for your excellent statements.

Our next witness is Arthur J. Grimes, of the National Health Council. You may proceed.

Unfortunately, I am in a very tight time bind. We will take your full statement and put it in the record as though it were read, and we would appreciate it if you would emphasize the highlights. I think you have sat through these last 2 days, and you might comment on how this matter is viewed by the National Health Council.

STATEMENT OF ARTHUR J. GRIMES, NATIONAL HEALTH
COUNCIL

MR. GRIMES. Senator Mondale, I think it is important for us to try to put some of this material on EFA in perspective. First, the Epilepsy Foundation of America is a member of the National Health Council. They were considered to be in substantial conformity with the National Health Council eligibility criteria and admitted to membership in December 1971, but they were admitted on the basis of not meeting fully certain of the criteria and needing very badly some help in terms of meeting some of these criteria.

We offered to provide assistance to them in doing this. One of the things they were particularly concerned about was greater public acceptance. ESA needed greater awareness that it was a reputable organization.

Our concerns at that time were really three:

(1) That the organization be democratically structured so that a greater proportion of the grass rooted people, those individuals who are contributing the money, have a say so about how it is spent;

(2) That the cost for raising money be brought into a more proportionate share of its total income or its total expenditures.

Our basis for what would be proportionate would be what would be within the normal range of such costs for other NHC voluntary health agency members.

There was even some concern about how adequately we can measure what is a reasonable fund raising cost ratio, and this was commented on in my testimony before the Committee in February.

(3) The third area had to do with promotion, publicity, and fund-raising practices.

In renewing the agency's eligibility for 1974, we feel that all of these criteria, with the exception of the high fund-raising cost have been adequately met.

We feel that the penny-letter does contribute rather strongly to their high fund raising costs. Mr. Funk and members of the EFA executive staff that we have talked with are quite cognizant of the fact that mail fund raising is expensive.

Senator MONDALE. What is the average fund-raising costs of your other house related charities?

Mr. GRIMES. As part of my statement today attachment B gives a breakdown of how the funds are spent by 15 of the council's voluntary health agency members. On it is the fundraising cost of each of these agencies as a percent of total expenses. This appears in column I.

[The chart referred to follows:]

NHC - December, 1973
FIFTEEN NATIONAL HEALTH COUNCIL VOLUNTARY HEALTH AGENCY MEMBERS
Program and Administrative EXPENSES as Percent of Total Expenditures, National and Affiliate Offices - 1971 or '72

Agency (Fiscal year ending)	A Total Expend.	B Research	C Public Ad.Prof. Ed.	D	E Comm.Serv.	F Patient Serv.	G Total Prog.	H General Manag. & Fund. Raising	I Total Admin.	J Major Equip. Ac.
American Cancer Soc. (8/31/72)	\$74,852,086	31.5%	16.5%	10.5%	7%	12.5%	78%	10%	18%	22%
American Heart Assoc. (6/30/72)	50,913,597	32%	12.5%	11.5%	15%		75%	12%	15%	27%
Mori. Easter Seal Soc. (8/31/72)	43,765,530	14%	2%	2%	64%	Inc. Pat. Serv.	69%	12%	13%	25%
American Lung Assoc. (3/31/71)	41,538,265	4%	16.5%	9.5%	30.5%	2%	62.5%	11%	24.5%	35.5%
National Foundation (5/31/72)	28,799,612	15%	15%	5%	13%	19%	67%	8%	23.5%	31.5%
Muscular Dystrophy Assoc. (3/31/71)	13,619,467	24.5%	11%	3%	8%	26%	72.5%	5%	28.5%	27.5%
Arthritis Foundation (12/31/71)	9,389,969	25.2%	15.5%	11%	20.5% (combined)		72%	14%	14%	28%
National Multiple Sclerosis Society (12/31/71)	8,087,618	19.5%	12%	6%	8%	25%	70.5%	10.5%	19%	29.5%
National Cystic Fibrosis Research Foundation (12/29/72)	5,154,559	30%	19%	2%	9%	8%	76%	7%	17%	24%
Epilepsy Foundation (12/31/72)	4,080,553	4%	9%	5%	26%	8%	58%	15%	33%	48%
National Hemophilia Foundation (6/30/72)	3,519,506	2%	3%	1.5%	2.5%	70%	79%	9%	18%	21%
National Kidney Fdn. (6/30/72)	3,091,957	25.5%	15%	8%	11%	15%	78.5%	10%	11.5%	21.5%
American Diabetes Assoc. (12/31/71)	2,603,774	9%	13%	11.5%	8%	31.5%	76%	11%	8%	19%
Natl. Soc. Prev. of Blind. (12/31/72)	2,593,377	6.5%	34.5%	16%	20%		71%	8%	15%	23%
American Social Health Association. (12/31/72)	634,830	27.5%	13.5%	2%	31%		74%	16%	10%	26%

Senator MONDALE. So for the Cancer Society you have 12 percent; for the Heart Association, 15 percent; for the National Easter Seal Society, 13 percent; American Lung Association, 24.5 percent; the Arthritis Foundation, 14 percent; the National Multiple Sclerosis Society, 19 percent; the Cystic Fibrosis, 17 percent; the Epilepsy Foundation, 33 percent.

Where did you get the 33-percent figure?

Mr. GRIMES. 33 percent is a consolidated financial report figure. The national office and all levels of operation combined.

Senator MONDALE. The local chapters?

Mr. GRIMES. The national and the local chapters are included. This is a consolidated report for 1972.

This is the amount of money for fund-raising as a percent of total expense.

Senator MONDALE. For Hemophilia, you have 12 percent; American Diabetes Association, 8 percent; for the Blind, 15 percent; for the American Social Health Association, 10 percent.

So that the Epilepsy Foundation is clearly the most expensive fund-raising organization of all.

Mr. GRIMES. Senator, in my statement—and it might be worth commenting on this—there is, I think, as much concern by the EFA Foundation as by most of us that their fundraising costs are high.

Senator MONDALE. How do they express that concern, by trying to hide the costs, by trying to recruit creative bookkeepers, or by reducing costs?

Mr. GRIMES. I notice that in some of your questions to persons presenting testimony earlier concern with the EFA methods for allocating their expenses, I think that is worth looking at a bit. I believe EFA is concerned with epileptics and concerned with trying to do something more for them than they have been able to do with the resources available. Thus, I believe that trying to spend less money for fundraising, management and general, expenses is an objective that they are striving to accomplish. How can they achieve this?

Maybe some of the problems is being able to take action on some fundraising and organization options that really may not have been given serious consideration by them as yet.

We are negotiating with them this year to go into an indepth analysis to help discover some of the options that may be used by them in terms of reducing some their costs, as well as improving some of their program service activities.

This will be done before the agency membership in the NHC is renewed for 1975.

Senator MONDALE. You say they have taken steps to reduce fund-raising costs. Did I understand you to say that?

Mr. GRIMES. Yes.

Senator MONDALE. What have they done?

Mr. GRIMES. What they have they done to date?

Senator MONDALE. Yes.

Mr. GRIMES. If you will look at the chart (attachment B) you will find that 26 percent of their program expenditures have been trying to create local chapters.

The organization is trying to diversify itself. It is trying to build

up at the local level so that they can move more of their fundraising efforts to a personal solicitation approach, which is less costly.

Making the shift overnight from the national office which has a centralized, very sophisticated computerized mailing operation nationwide, to a local operation cannot be done overnight; you have to have something local to pick it up, and they are trying to build a local structure, where there is none, strengthen the existing structures, so that they can carry out a good fundraising campaign and a good program service campaign, because continuing fundraising success depends upon program.

Senator MONDALE. Do they want to get out of the mail order business?

Mr. GRIMES. Getting out of it will depend on how successful they are in getting people to volunteer to ask their fellow citizens for contributions to the epilepsy cause.

Senator MONDALE. How accurately do you think they reflect the fundraising costs in their public disclosure?

Mr. GRIMES. The rules for how to allocate costs in voluntary health agencies is well established. I was a little disturbed by the emphasis in earlier questions on trying to look at how much time Mr. Funk spends on fundraising. Actually Mr. Funk has total responsibility for the organization. For a top executive to be able to allot the time he spends for fundraising, unless he does it 1 week at a time and is able to go back and recapture it by looking at his calendar, is very difficult to do.

As a result, most of the executives that have generalized responsibility have salaries that are put in "Management and General"—a supportive service category as is "fundraising."

Senator MONDALE. Now, you have eight people opening envelopes who come in after the mail goes out. None of that is charged to fundraising. Would your council approve that allocation?

Mr. GRIMES. The standards of accounting for voluntary health and welfare agencies are basic in an organization of this kind—all of our other volunteer health agencies use this as a basis for financial accounting and reporting. The rule on this is that the activities that are concerned with keeping records of how much money is received and where it is to be put is a proper accounting practice. It would be put into accounting and recordkeeping function, just as other recordkeeping practices.

Senator MONDALE. In other words, the accounting standards of the National Health Council say you can have a staff there opening up mail in response to mail solicitation, and it is perfectly proper that none of that should be allocated to fund-raising?

Mr. GRIMES. That is right, because this is a record keeping function.

However, Senator, the "thank you" notes for those contributions is a proper fundraising expense.

Senator MONDALE. You also say that the top executives, even though some of their time is spent on fundraising matters, find it perfectly proper not to have that allocated to fundraising, is that right?

Mr. GRIMES. It is difficult and time consuming to keep minute records. A staff person who is operating in all areas, that is, when he

goes out to talk to a group, may have a municipality of reasons; one of them is fundraising, one is to make sure they have information about the disease entity, etc. He might have a variety of functions he is fulfilling.

Senator MONDALE. Anyway, it is accepted that they will not allocate any of it to fundraising.

Mr. GRIMES. Unless it is major, direct responsibility for a material amount of time otherwise it is management and general and that is considered a supportive service, just as is fundraising.

Senator MONDALE. Suppose a manager spends 40 percent of his time in fundraising?

Mr. GRIMES. Then that would be put in fundraising.

Senator MONDALE. What is the cutoff?

Mr. GRIMES. There is no specific cutoff point. If you have a person spending a material amount of his time in any one program activity, i.e. enough that begins to bite into enough that warrants the time and effort to keep records, to, I would say in terms of a week at a time for a particular function because of special problems, then for the agency's purposes they should keep records of how he is using his time for that function. It is not just a matter of accurate reporting; the agency needs to know for good management purposes how much is spent for fundraising, how much for administration, and how much for each program.

Senator MONDALE. Now, they had five regional managers, one of whose key function was to go around and set up local chapters, teach them how to raise money, and so on. None of that is allocated to fundraising.

Is that consistent with your council standards?

Mr. GRIMES. The regional directors?

Senator MONDALE. The regional managers.

Mr. GRIMES. Senator, the prime function of these people is to provide a generalized consultation service at the local level. In some instances, the time for these people can be allotted I would suspect, into types of activities, because there is a fund-raising period and I would suspect that a lot of a manager's time at that season is directed toward fundraising and should be so apportioned.

Senator MONDALE. It should be?

Mr. GRIMES. It should be. However, he is still a generalist. The practicality for judging whether to allot by specific function depends on whether he is directly supervising a function for a material amount of time.

Senator, there is a paragraph in the standards that I think is important for the record.

[The following material was subsequently supplied for the record:]

[From the Statements of Accounting for Voluntary Health and Welfare Agencies]

How, then, should informational materials and activities that combine inextricably elements of public education, administrative reporting and potential future fund raising be accounted for in an agency's published statements? The logical basis for accounting for and reporting such activities is that they are "general" in purpose, supporting several of an agency's primary services

(including fund raising)—and comparable, therefore, with the managerial, legal, accounting and other activities previously identified as "Management and general" expenses. Thus, "administrative reporting" and other non-educational, non-program and non-fundraising (as previously defined, in each instance) informational materials and activities are to be accounted for in an agency's Exhibit A as "Management and general" expenses.

Mr. GRIMES. That is the rule and rationale for allocations to this category of supportive services.

Senator MONDALE. You listened to their testimony yesterday and today on accounting, and there was testimony that there was nothing that they were doing that was contrary to those standards, or the Council's regulations.

Mr. GRIMES. Senator, I am not sure I was here when they were talking about this. I was in and out.

However, let me say this. The National Health Council depends on what happens in terms of accuracy of agency allocations on the professional independent CPA audit. It is the responsibility of the CPA when he goes in to audit, to determine whether or not there is proper controls on accounting for allocations.

Senator MONDALE. So you do not as a council look at the allocations process at all?

Mr. GRIMES. We do not unless the CPA qualifies his audit. This would be the same as you would do for a business firm. You would not question a CPA's opinion without cause.

Senator MONDALE. Of course a business is not using other people's money.

You accept a certified audit, and you would not look behind it to see how the money was allocated for the fundraising and other purposes.

How does the accountant know how to allocate it?

Mr. GRIMES. The CPA or independent auditor has in the past had a number of options for auditing of voluntary health and welfare agencies. There has not been any universal auditing standard. As of June, 1974, the American Institute of Certified Public Accountants has adopted the principles of the uniform accounting standards published by the NHC and the national assembly in 1964, as the official auditing process for voluntary health and welfare agencies. Differences in auditing procedures from what the AICPA audit guide for this field—based on the uniform accounting standards—call for will now be questioned by the auditing profession. Thus, there is only one way for the fiscal years' beginning after June 1974.

The problems in the past have been that an auditor not familiar with unique problems of voluntary and health and welfare agencies would often use business world auditing practices. This created confusion. We suspect there will be improvement, as a result of moving towards what is now mandated standards based upon the uniform accounting standards.

Senator MONDALE. We had testimony today by health professionals that the materials and information being submitted to the public by the Epilepsy Foundation was inaccurate if not misleading. Does your council get into that literature?

Mr. GRIMES. Yes, Senator. I think it would be wise for us all to try to put that into perspective.

EFA has some very outstanding neurologists who are as familiar if not more so than the gentlemen who were sitting at this table this morning.

The PAB—professional advisory board—of EFA has a rather distinguished group of scientists. They are expected to approve the content in the materials that go out.

Senator MONDALE. Which scientists are on their board?

Mr. GRIMES. A. B. Baker, M.D., Ph. D., founder and past president of the American Academy of Neurology, past president of the American Neurological Association, head of the department of neurology at the University of Minnesota, past chairman of the professional advisory board and currently chairman of the board of the Epilepsy Foundation of America; A. L. Sahs, M.D., current chairman of the foundation's professional advisory board, past president of the American Academy of Neurology, past president of the American Neurological Association and head of the department of neurology at the University of Iowa; and David D. Daly, M.D., Ph. D., chairman-elect of the foundation's professional advisory board, president of the International League Against Epilepsy, a member of several governmental advisory committees on the epilepsies, and professor of neurology at the University of Texas Southwestern Medical School at Dallas.

Senator MONDALE. Does the council itself look at the accuracy and validity of these standards?

Mr. GRIMES. The National Health Council looks at the ingredients of the organization in terms of what it has, in terms of support for putting out scientific material. If that organization has reputable scientists as part of its advisory board, why should we develop another advisory board to look at it?

Senator MONDALE. In other words, the council accepts the certified audit that takes care of the business side.

Mr. GRIMES. Unless somebody raises questions about it, Senator; then if they do, we look into it further.

Senator MONDALE. Have you looked into the Epilepsy Foundation?

Mr. GRIMES. We are in a process of doing so this year. We are going into it with an indepth on site visit review that takes, incidentally, a large investment of staff time.

If we did this for every agency, we would be setting up another policing force. The point is we have to trust these organizations until questions are raised by the materials they supply to us.

If there is a certified public accountant, certifying that these organizations are following professional standards, we are going to accept their point of view, their documented evidence, until somebody raises a question about it.

Senator MONDALE. Would you look into this literature now that you have heard the testimony this morning?

Mr. GRIMES. Yes, we will. Incidentally, I talked to Dr. Harting earlier at the February meeting. Dr. Harting called me aside and asked me if I was aware of some of the material they were putting out. I went back, got the material that had been supplied to us by the Epilepsy Foundation of America, I found that the data on

prevalence is backed up by reputable scientific authorities including the National Institute of Neurological Disease and Stroke.

Even before coming to these hearings we wrote to the Health Statistics Section of the DHEW and asked them for prevalence data. There is nothing inconsistent with the 2 to 4 million prevalence estimate used by EFA.

So it is consistent with reputable scientific professional organizations.

Senator MONDALE. In other words, you are prepared to certify this accuracy—

Mr. GRIMES. From the data that are available to us, it is based upon reputable scientific knowledge, the best that is available.

Senator MONDALE. You have made an independent study of it?

Mr. GRIMES. We have looked at it, checked back in terms of other sources that are available in this particular area.

Senator MONDALE. Your council did?

Mr. GRIMES. The National Health Council.

Senator MONDALE. Who on your staff did?

Mr. GRIMES. I did.

Senator MONDALE. And you are willing to certify this morning this material as accurate?

Mr. GRIMES. Senator, it is accurate to the extent that other scientists can verify that it is on a sound basis. That is as much as we can do, because we do not do independent surveys of how many epileptics there are in the country. We try to go to the recognized sources in these areas.

We have asked, "Is there anything wrong with this estimate? What is the estimate for it?" The Government is one of our main resources for such information.

Senator MONDALE. What about the testimony about the EEG effort in San Diego where according to one witness this morning there was a document from the foundation indicating this remarkable work was going forward because of a grant from the foundation when in fact it was discovered that Dr. Dickford was doing work primarily on the basis of a \$394,000 grant from NIH?

Mr. GRIMES. Is this the question of how much money a researcher is getting from government and from the voluntary organization, from the Epilepsy Foundation? Is that the question, Senator?

Senator MONDALE. That is the question, yes.

Mr. GRIMES. EFA, as you noticed, is spending approximately 5 percent of its total expenditures at all levels for research.

Senator MONDALE. We are talking money about this particular grantee.

Mr. GRIMES. EFA, in spending money for any one researcher tries to spread this out to try to provide as much stimulus as possible.

There is no question that most of the scientific research in the country is financed by the Federal Government, many researchers also receive money from private foundations.

For EFA to acknowledge all of its researchers' sources for funds is questionable, but I think that any voluntary organization ought to indicate if they are one of several contributors supporting research on any particular project.

This is standard operating procedures as I understand it for agencies acknowledging support.

Senator MONDALE. This is what it says. The EEG system has been developed under an EFA grant to obtain the University of California's regional director, Dr. Brickford, to head the project. He is assisted by others, and there is no mention of the fact that \$300,000 was granted by the NIH.

Mr. GRIMES. Senator, do you know for a fact as to whether or not that went to specifically the same project, for the same purpose?

Senator MONDALE. Yes; it went to Dr. Brickford under the grant 5R-01-NS-08962.

Mr. GRIMES. Was this the specific project that EFA is claiming credit for?

Senator MONDALE. That is what the testimony was this morning.

Mr. GRIMES. I would agree that there should be acknowledgement if this is partial support for the same research project; yes. If it was not done, it was unfortunate.

Senator MONDALE. Unfortunately, I am going to have to leave the hearing at this point, and I will ask Mr. Funk, who I think has some more to say, to submit his reaction to the testimony this morning in writing.

I would ask the witnesses who had earlier testified about programs to respond to Mr. Grimes' statement that the representations in the foundation's material are accurate and responsive, and if further hearings are indicated following that information, we will proceed.

The next witness is Mr. Gordon. I simply must leave.

Mr. GRIMES. Incidentally, there were some statements this morning about how adequately the National Health Council is carrying out its functions, and I think in all honesty that needs to be addressed.

I do not know whether you want that done at this point.

[The prepared statement of Mr. Grimes follows:]

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Statement to the Senate Subcommittee
on Children and Youth
of the Committee on Labor and Public Welfare

April 9, 1974

by

Arthur Jack Grimes
Director for Membership
National Health Council
New York, New York

Subject: THE EPILEPSY FOUNDATION OF AMERICA

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Statement to the Senate Subcommittee
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Subject: THE EPILEPSY FOUNDATION OF AMERICA

Mr. Chairman and Members of the Committee: Thank you for your invitation to testify on the Epilepsy Foundation of America and this organization's relationship to the National Health Council. I am Arthur Jack Grimes, Director for Membership of the National Health Council.

At the Committee's hearings on February 4, 1974 on the general subject of "Charitable Organizations that benefit Children," I presented background information on the National Health Council and its 75 member organizations. A general description was provided of the standards these organizations must meet to be an NHC member. Included also in my earlier remarks was information on the importance of the voluntary health movement and a description of the functions of these agencies. Emphasis was given to the criteria for ethical fund-raising and promotion publicity met by NHC member organizations and to some cautions on the use and limitations of financial ratios in judging the efficiency or effectiveness of charitable organizations. In conclusion, three proposals were submitted for national legislation to encourage improvement of the human condition through voluntary citizen action including the health of children and youth.

The information presented in my February 4 testimony is relevant to consideration of the Epilepsy Foundation of America and its practices. I will not, however, repeat any of my earlier testimony today since it is available to the Committee from the Congressional Record of February 19 (pages 1852 thru 1855), unless specific parts of this information is requested by the Committee during the question period. For reference today basic information on the purposes of the National Health Council and a list of its member organizations is included as part of this statement in ATTACHMENT A.

My purpose in appearing before you today is to examine the relationship of the Epilepsy Foundation of America to the National Health Council and the special conditions that relate thereto.

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From the information required to be submitted to the National Health Council by this organization, they meet substantially the Council's criteria for eligibility for this membership category. Originally accepted for Council membership in December, 1971, they were approved by the NHC Board in December, 1973 for 1974 continuing membership as a Voluntary Health Agency Member with the condition that the criteria not fully met at this time, will be by the end of the year.

The NHC Role in Development of a Unified National Focus for Voluntary Citizen Action Against Epilepsy

Ignorance, fear, shame, despair, these are words with great intensity of meaning, which have been associated with epilepsy, a condition which affects an estimated two to four million people in the United States.

Over the years, it is natural that the needs of persons afflicted with this tragically "different" condition brought them, and others concerned about them, together in communities across the country. The purpose and focus of these groups varied. For some it was to develop understanding of epilepsy; for others to encourage and establish services for epileptics; for still others, it was primarily the solace of association with people having kindred problems.

By 1957 there were three epilepsy organizations in the United States which had extended their interests and activities to some degree beyond the community level. They were: The Epilepsy Foundation in Washington, D.C.; the National Epilepsy League in Chicago; and the United Epilepsy Association in New York City.

The American League Against Epilepsy (now the American Epilepsy Society), a medical-scientific organization concerned with research related to understanding and curing epilepsy, sponsored a workshop in 1957. This brought together for the first time many lay persons, including representatives from the three major voluntary epilepsy organizations, who shared an interest in the problems of epilepsy. Out of this workshop came an expressed desire for a single national voluntary organization which would be "truly representative of the many geographically scattered epilepsy societies currently rendering services throughout the United States."

Two years later another organization in this field, the American Epilepsy Federation, was formed. It brought together in a federated structure a number of community epilepsy groups, but the three lay organizations with "national" objectives did not join the Federation. Thus there were now four voluntary "national" organizations in this field. Epilepsy is a major health problem in this country but, until the mid 1960's, there was no single forceful, nationally recognized voluntary organization which could assume leadership on behalf of those affected by epilepsy.

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Because of the fragmentation, the National Health Council offered its auspices in the early 1960's to the four organizations in order to give leadership in the formation of a unified organization and creation of a national voice on this subject. In extending its "good offices" to the epilepsy organizations, the Council was taking on a role of facilitating services to people affected by the same health problem. In addition to financial support from the epilepsy organizations concerned, negotiations through the National Health Council for a stronger voluntary voice in the epilepsy field were supported in part by a grant (RB 1202) from the Vocational Rehabilitation Administration, Department of Health, Education and Welfare, and by a contract (PH 8662175) with the Public Health Service, also in the Department of HEW. These negotiations were begun in December, 1961, and eventually resulted in a series of mergers. This culminated in December, 1964, in the formation by three of the original four groups of a new national agency concerned with epilepsy, the Epilepsy Association of America (EAA).

The agency that was not immediately a part of the merger was The Epilepsy Foundation (TEF). On July 7, 1967, however, the boards of the new Epilepsy Association of America (EAA) and The Epilepsy Foundation (TEF) finally consummated a plan for merger. The resulting group is the subject of today's hearings - The Epilepsy Foundation of America (EFA).

Thus, the National Health Council was reasonably successful in its original objective of assembling in one national organization the potential for combining the efforts of the many people who believe that only through unified efforts can the mastery of misunderstanding and prejudice that surround epilepsy give way to enlightenment and understanding.

EFA - 1969 Application for NHC Membership

Initially, the new epilepsy organization, EFA, did not meet several of the "Essential" NHC membership requirements. The eligibility criteria not met were:

1. A board of directors elected by a constituency significantly larger than itself.
2. An annual report to the public that includes:
 - a. consolidated national office and affiliate organization financial reporting to the public according to the Standards of Accounting and Financial Reporting for Voluntary Health and Welfare Organizations. (NHC-NASPO)
 - b. geographic locations of board members (for public information on degree of national representation).

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3. Ethical methods of fund-raising. Specifically, the EFA's practices, inherited from the earlier Washington, D.C. based group (TEF), of renting to others its own mailing lists and distribution of mailing labels ("unordered merchandise") with commercial market value as part of its solicitation appeal, were not acceptable in meeting the National Health Council standards.
4. Does not devote a disproportionate amount of organization's annual resources to fund-raising, administration and other "non-program" activities.

(For most new voluntary movements, greater initial investments in staff and board member recruitment, organization and training are required. Normally, these should level out after the first two or three years. In 1970, four years after its founding, the EFA supportive services costs (i.e. fund-raising and general administrative management) exceeded 50% of its total income. In its fifth year after merger, these costs for EFA were still not within the normal pattern for such costs of the other NHC National Voluntary Health Agency Members. These costs for others range from 20 to 36% of total expenditures.)

Most of us viewed the above problems with meeting our criteria as temporary, some more significant than others, but all amenable to solution by a new board with increased vigor for public acceptance and growth. These were initial barriers to NHC membership that most felt could and would be resolved. Some were expected to require more time to resolve than others. Beginning in 1969, the EFA worked closely with the National Health Council to examine procedures used by other Voluntary Health Agency Members to accomplish the Council's standards.

EFA - Accepted as a National Health Council Voluntary Health Agency Member for 1972

By November, 1971, the Council Board found that EFA had accomplished the following:

1. Restructured its bylaws to provide for election of a board of directors by a membership constituency larger than the governing board and representative of the various sectors of the country including its affiliated organizations at the grass-roots level. The bylaw changes provided for a democratic process for governing board participation by a broad spectrum of its supporters from all levels of operation, lay and professional.

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2. Developed plans to report 1971 finances, for national office and affiliates combined, to the public according to the financial reporting Standards and to identify the national board members by their geographic area in its annual report.
3. In relation to fund-raising, the EFA had:
 - Procedures underway for protection of donor confidentiality.

(Adopted a policy against selling or renting its mailing list.)
 - Plans to eliminate use of mailing labels with commercial market value as part of its fund-raising appeal.
 - Initiated plans to phase out the "penny letter" appeal. I would like to point out here that the National Health Council is concerned with the mailing of money as part of a fund-raising appeal. A penny does have market value and thus can be considered "unordered merchandise." From a practical point of view, however, the Epilepsy Foundation of America has experimented with a number of ways of making its appeal for contributions to the epilepsy cause and, we are told, has found none as successful as enclosing a bright shiny new penny as part of its appeal letter. Based on this, the NHC Standards and Practices Committee concluded that the financial value of a penny in today's market has more value as a symbol or logo for the epilepsy appeal than it has significance in relationship to something of real value to the receiver. Our major concern at present, in relation to the "penny letter" is its contribution to EFA's costs for mail solicitation.
4. Adopted and was implementing a plan to reduce its fund-raising costs. Included as part of this plan was a phasing out of the "penny letter" which, as indicated, was seen, by both EFA and NHC, as a contributing factor to fund-raising costs higher than that for most other reputable voluntary health agencies.

In considering the EFA as a possible NHC member in 1971, we reviewed the above developments. The first item, restructuring to provide greater participation from parties of interest at all levels, was completed. The remaining three steps in removing barriers to NHC standards were in progress, but yet to be carried out to completion.

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The ultimate NHC decision was based on the purpose for the Council's standards for membership and how they can best be used for improving the health of people:

TO STRENGTHEN THE OPERATION OF ORGANIZATIONS ENGAGED IN IMPORTANT HEALTH CAUSES AND NOT BE RESTRICTED TO SEPARATING THE "WORTHY" FROM THE "NOT-SO-WORTHY" GROUPS.

With this philosophy and objective as the base, the National Health Council Board approved the Epilepsy Foundation of America for NHC membership for 1972 with a qualifying condition:

That the NHC criteria, not fully met, be satisfactorily accomplished over the next three years with documentation of progress towards accomplishing these criteria to be provided annually to the NHC. This three-year period terminates at the end of 1974.

For EFA continuing eligibility in NHC, the disproportionate amount of money for fund-raising was, and is, a major concern. In making a decision to accept the Epilepsy Foundation of America into the National Health Council for 1972, the following factors were considered as contributing to the higher than average cost for raising money for this agency:

1. The nature of the disease - epilepsy has a stigma of being a social and occupational handicap to persons so afflicted. People do not want to be identified as having epilepsy so they do not readily volunteer to help publicly raise funds because of the fear of the stigma that it has for them personally. The anonymity of a mail solicitation is one answer to this problem and one that has worked with considerable success for the Epilepsy Foundation of America and one of its predecessors, The Epilepsy Foundation (TEF), in raising funds needed for the many problems that exist for epileptics.
2. Epilepsy, as a major health problem is not well accepted or recognized. The fight against epilepsy is not as well known as that of some other diseases such as heart disease or cancer. The toll on human suffering, social and occupational handicaps is not as well known. The feeling is that this lack of information is due to a considerable degree to the lack of resources for providing the public with more information.
3. The relative newness of EFA and the need for greater awareness of EFA as a reputable voluntary health organization - one of the most frequent difficulties EFA originally reported in attempting to obtain volunteers for personal (and less expensive) solicitation was whether or not they were accepted by the National Health Council, the National Information

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Bureau or one of the other "approving agencies in the field.

4. Its dependence for 85% of its total public support on mail solicitation - an agency which places most of its emphasis on mail solicitation is bound to incur higher expense than one which does not. Yet raising money by mail is a legitimate method of appeal and has served a few respected national agencies well for a long period of years. Organizations that use mail solicitations tend to have higher fund-raising costs. Increasing postal rates and costs for materials encourage such groups to diversify their solicitation methods as rapidly as they can in order to reduce the supporting services costs. They tend to move into less costly techniques, such as personal solicitation, as their cause becomes known and publicly accepted.

EFA - as an NHC Member

Over the past two years, EFA annually documented progress towards meeting fully the NHC criteria while also increasing their annual income and programming to serve epileptics. In the last such report received, in 1973, for EFA activities and accomplishments during 1972, there was full conformity with all but one of the conditions for its continuance as a Council member beyond 1974 ---- EFA's cost for fund-raising.

EFA's first financial statement that consolidated information for all operational levels, i.e. all chapters and the national office, was issued in 1972. (6-1972). Any comparison of 1971 figures with earlier figures for the national office only, therefore, is not valid. Fund-raising cost for the total organization on a consolidated basis in 1972 was 33%. From the evidence available to-date, EFA reports to us that they expect the consolidated figure for fund-raising costs for 1973 will be approximately 30% - a reduction of 3%. (Fund-raising cost reported for the national office only in 1971 was 43%, for 1972 40%.)

ATTACHMENT B to this statement is a chart of the program and supportive costs (i.e. "Fund-raising" and "General Administration") as a percent of total expenses for national and affiliated offices for 1971 or 1972 for 15 of the National Health Council's Voluntary Health Agency Members. The percentage cost for fund-raising for the Epilepsy Foundation of America leads the list.

On balance, I would like to emphasize a point brought out by the Council of Better Business Bureaus in one of their recent publications. "Many groups which spend little on fund-raising have comparatively ineffective programs of public service." There seems to be a pre-occupation with the fund-raising cost ratio in judging how worthy an agency is for public support, while lesser attention is given to organizations that have a minimum productivity from charitable efforts. While law enforcement agencies under some regulatory laws can put a stop to solicitations by organizations because their

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fund-raising cost ratios exceed 25 or 30% of income, the law does not bother to touch groups which raise money inexpensively but whose accomplishments are minimal.

Even though EFA has a cost for raising money that is still beyond the normal range of the other NHC members, it is addressing itself to reducing these costs.

Next Steps

Since continuing eligibility for EFA as a Council member for 1975 will depend upon some rather definitive answers as to what can be done about reducing its supportive services costs, the Council and the Foundation currently are negotiating the possibility of an in depth cooperative analysis of the EFA's operations before the end of 1974. Our mutual purpose is to identify what improvements are feasible in the EFA's operations, consistent with the NHC standards, with the primary objective of increasing services to epileptics.

Mr. Chairman, reports submitted to us evidencing progress and the complete cooperation by the Epilepsy Foundation of America leaves us little basis to question the sincerity of the leaders of this organization in desiring to do a better job for epileptics. We support them in this task. Changes are needed to enable them to continue to meet the Council's standards. We expect these changes will be made without sacrificing the quantity or quality of services that are important to combat epilepsy. If we find that this agency will have to sacrifice, on a continuing basis, needed services to its constituency in order to fit into a pre-set universally applied fair ratio of fund-raising costs to total income, we may need to adjust our thinking to the realities of the situation and encourage flexibility in applying any such simple test for worthiness of public support.

Our major concern and, we believe, that of each member of this Committee, in regards to the Epilepsy Foundation of America, is to improve the organization's operations without doing damage to its vitality and potential for improving life for the estimated two to four million epileptics in the U.S.A.

ARTHUR JACK GRIMES

April 9, 1974

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ATTACHMENT A

WHAT THE NATIONAL HEALTH COUNCIL IS AND DOES

The National Health Council was founded in 1920 by a group of leaders who anticipated a vast expansion in health activities and foresaw the need for a meeting ground and coordinating mechanism for the growing number of national health agencies in the United States.

The National Health Council's goal is to improve the health of the public throughout the nation by:

- Improving accountability and credibility of the private* sector including outreach to groups not meeting present membership criteria;
- Representing and promoting the needs and contributions of the private sector in health affairs;
- Providing a channel to and from government by serving as a point of communication, a coordinated point for exploring and clarifying public issues and reviewing and appraising for the public and private sectors the programs and policies of the public sector;
- Providing linkage to the total health scene for its members;
- Augmenting the objectives and efforts of members and fostering and encouraging mutual assistance to improve effectiveness of performance;
- Participating in public policy development through exploration of policy issues.

*By this is meant voluntary health agencies, professional associations, proprietary health institutions, and other organizations, agencies, and corporations having an interest in the improvement of health of the public.

The Council's activities are charted and guided by a 43-member Board of Directors. The Board consists of 24 directors elected by the Membership and 7 Officers and 12 Counsellors elected by the Board.

Incorporated under the Laws of the State of New York, the National Health Council is a 501 (c) (3) tax-exempt organization. Dues and service fees from member agencies constitute the major continuing source of income.

NATIONAL HEALTH COUNCIL
1740 Broadway, New York, N. Y. 10019
(212) 582-6040

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Membership of the National Health Council*

ACTIVE MEMBER AGENCIES

American Association of Blood Banks
American Association for Respiratory Therapy
American Cancer Society
American College Health Association
American College of Preventive Medicine
American Dental Association
American Diabetes Association
American Heart Association
American Hospital Association
American Lung Association
American Medical Association
American Medical Technologists
American Medical Women's Association
American Nurses' Association
American Occupational Therapy Association
American Optometric Association
American Osteopathic Association
American Pharmaceutical Association
American Physical Therapy Association
American Podiatry Association
American Public Health Association
American Social Health Association
American Society for Medical Technology
American Speech and Hearing Association
Arthritis Foundation
Association of Medical Rehabilitation Directors and Coordinators

Association of Schools of Allied Health Professions
Association of Schools of Public Health
Blue Cross Association
Epilepsy Foundation of America
Eye Bank Association of America
Muscular Dystrophy Associations of America
National Association of Blue Shield Plans
National Association of Home Health Agencies
National Association for Music Therapy
National Council on Alcoholism
National Cystic Fibrosis Research Foundation
National Easter Seal Society for Crippled Children and Adults
National Environmental Health Association
National Foundation
National Hemophilia Foundation
National Kidney Foundation
National League for Nursing
National Medical Association
National Multiple Sclerosis Society
National Safety Council
National Society for Autistic Children
National Society for the Prevention of Blindness
Society for Public Health Education
Student American Medical Association
Student National Medical Association
United Cerebral Palsy Associations

ASSOCIATE MEMBERS

American Foundation for the Blind
American Home Economics Association
American National Red Cross
Association of Junior Leagues of America, Inc.
Equitable Life Assurance Society of the United States
Goodwill Industries of America
Health Insurance Council
Lions International
Metropolitan Life Insurance Company
National Association of Social Workers
National Council on the Aging
National Council for Homemakers-Home Health Aids Services
National Dairy Council
National Federation of Business and Professional Women's Clubs
National Rehabilitation Association
National Urban League
Smith Kline & French Laboratories

FEDERAL AGENCY MEMBERS

United States Department of Agriculture
Federal Extension Service
United States Department of Health, Education and Welfare
Office of Education
Public Health Service
Social Security Administration
Social and Rehabilitation Service
Veterans Administration, Department of Medicine and Surgery

*As of December 1973

National Health Council, Inc.

Edward H. Van Ness, Executive Director
1730 Broadway, New York, N.Y. 10019

212 502-6040

Senator MONDALE. I would like to have you back, and I would like to go into these very bland generalized statements of support we have been hearing the last half hour, and I would be glad to go into it in great depth.

Mr. KATZ. Our next witness is Harold Gordon, counsel for the Epilepsy Foundation of America.

Mr. Gordon, we are going to have to adjourn shortly, so we would appreciate it if you would keep your testimony brief.

**STATEMENT OF HAROLD GORDON, ESQ., ATTORNEY FOR
EPILEPSY FOUNDATION OF AMERICA**

Mr. GORDON. Mr. Katz, I am a great believer in due process, and the opportunity to be heard. I recognize your position. I think you ought to know I have one, and I have an obligation on the House side in a half hour, so you know I will not keep you very long.

A statement was made this morning with regard to the State of Pennsylvania. Since I understand at least one of the legislative purposes of this committee is to determine the effect of various State laws, I am doing something I would not normally do, and that is to comment on a case that is presently in litigation.

The director of the Charitable Solicitations Commission of the State of Pennsylvania testified here this morning and stated that we have been denied in Pennsylvania and an appeal was taken.

I think a fairer statement may have been that the solicitations commission did act, and the foundation was denied, and that an appeal was taken, and that the Commonwealth Court of Pennsylvania, in its discretion, acted and stayed the effect of the denial.

For the record, I will read into the record one paragraph of the order given in the case of the Commission of Charitable Organizations, versus the Epilepsy Foundation of America in the Commonwealth of Pennsylvania:

And now this 29th day of March, 1974, upon consideration of the Epilepsy Foundation of America's Petition for Supersedeas, and after oral argument, it is hereby ordered and decreed that the order of the Commission on Charitable Organizations denying the renewal application of the Epilepsy Foundation of America is stayed, and the Epilepsy Foundation of America is permitted to solicit funds and engage in fund raising activities in the Commonwealth of Pennsylvania pending final disposition of the appeal in this matter.

I think one of the problems we have here is you have 51 States including the District of Columbia with varying State laws. I think Pennsylvania is perhaps an excellent example to the problems you face, and that the persons in the voluntary health agencies face, and the National Health Council faces.

There is a veritable jungle of statutes. Some of them are very tight, some of them are very loose. I believe that in the Senator's own State of Minnesota the only thing that is required is an audited statement. This is true in many other jurisdictions.

Under statutes of that nature I think it would be possible to raise funds for the widow of the unknown soldier as long as he made full disclosure and had an audit.

I think also the way these statutes are enforced is rather interesting in many areas, and I would point out, just to correct the record, there

have been several references to the testimony about the 50-percent rule in New York. There is not a 50-percent rule in New York. There is a 50-percent rule in New York only if you are operating a mail operation, and you are using unsolicited merchandise. There is no 50-percent rule in New York otherwise.

I would also suggest that the Pennsylvania statute is a perfect example of confusion on how problems arise. It has been previously testified the foundation became a member of the health council in 1972. The first year that it attempted to meet health council standards was the fiscal year 1972.

In October 1972, the Commonwealth of Pennsylvania through its legislature amended a then 9-year-old law that was originally enacted in 1963. One of the main thrusts of the amendment of 1972 was to put in a 35-percent fundraising cost limitation on, and so suddenly in October 1972 charities were told they had to meet a 35-percent limitation, although they had been keeping their books in accordance with the generally accepted accounting methods, and with the health council rules which had no such reference.

It is a little difficult to go back over 10 months and redo your books.

I would also point out that one of the other problems with the Commonwealth of Pennsylvania is in the original statute enacted in 1973, and on the statute books since then, there is a little sentence that says the commission shall have the power, and its duties shall be to promulgate rules and regulations and prescribed forms for the registration or other purposes consistent with the specific requirements of this act.

Interesting enough, in 11 years the Commonwealth of Pennsylvania has not bothered to enact any regulations insofar as charities are concerned, and when this matter first came up, I flew up to Harrisburg to see if I could resolve it.

I met with the deputy attorney general who assured me that there were in fact no regulations—I think his comment was that they are on somebody's desk.

Even when I was an attorney for the Government, things did not sit on someone's desk for 11 years—at least I hope they did not.

But I would also point out that at the hearing a regulation was shown to us, and we finally discovered after some discussion with the commission and with the attorney for the commission, that it was an interesting regulation, but it was not applicable to what we were talking about.

It gets very difficult as an attorney to advise a client what to do in a situation like this. I think Senator Mondale would recognize this, since I know he is an extraordinarily fine attorney, but you have a plethora of State statutes. This book I have here [indicating] is the result of our efforts to find out what they all say, and it is rather difficult.

There are places you can go to get little charts that say where you have to register and everything, but they do not give you the statutes, and it is a little difficult because they are constantly changing, but we have made the attempt to do this.

As far as Pennsylvania is concerned, I think it is indicative of the problem we have with State laws. The commission has really just gone into operation. I am sure they are intent on doing a good job. They however have no rules. They have no regulations. The statute in my judgment is probably defeatable simply because they have not bothered in 11 years to promulgate regulations.

The fact remains that they have set a 35-percent limitation. Their forms speak in terms of one thing, however, health council standards. They also ask you to use a crystal ball because they want to know how much you expect to raise and how much you expect to spend. It is rather difficult to use a crystal ball.

The problem with the statute is not even the people in Pennsylvania understand it. When we did file our appeal, they set the appeal for some 18 days after the decision, and when we pointed out that the statute required that the appeal be heard in 15 days, they did not agree with us.

The next day we received a telephone call, and apparently somebody had read the statute, and so the hearing was moved up 4 days.

This is not to knock the Commonwealth of Pennsylvania or the commission that is trying to do a job, but it is a commission that is operating under a law that they have not seriously worked on yet, and they are feeling their way. There are no grandfather rights in it; there are no rights to allow an organization to get into compliance.

The difficulty is the statute talks of the health council standards but they do not know what they are. They ask for a breakout of expenditures on a functional basis; 1972 was the first year that the foundation kept its books in accordance with the health council principles.

They have been trying to do so for several years, and they finally achieved it with the chapter membership, but there are over 100 chapters which are manned by volunteers. They do not have the money, they do not have the authority, and they do not have the knowhow to handle their functional expenses on a breakout basis such as required by the health council.

We have been trying to get them to do it. We think we are going to be more successful this year. But in fairness, if you use a combined statement for this organization, you come up with a 32.9-percent fundraising cost ratio.

It is impossible for the year 1972 to comply with the statute that was passed in October of 1972, that now requires you to do it.

It would have meant going back to every single chapter and telling them to redo their books. We were able to give them this breakout on the national basis, and we were perfectly willing, and we had Price Waterhouse there to testify to break it out on an extrapolation basis for the rest of the chapters, with the understanding that it was best judgment and nothing more could be done.

I would have grave difficulty in asking over 100 chapters to redo their books at this point. I think if you will look at the statements submitted to you by New York, the New York chapter which Mr. Self described, it is a sophisticated chapter, but they do not keep their books this way. We will try to get them to do it, and I am sure they will this year.

I think it is totally unfair for a statement to be made by a Pennsylvania official that EFA has been denied, and not to also state that an appeal has been taken and the denial stayed.

I think if this committee is to serve any useful function there must be a uniformity of State statutes or a preemption by the Federal Government, one or the other with a uniformity of forms.

I am quite sure that if you looked at the forms and applications filed in the jurisdictions that required it, the numbers are going to be different for every voluntary health organization that files.

The simple reason is the questions are different, and you must answer the questions. You must be responsive to those questions.

I would think that the best function that could be served by this committee would be uniformity of State statutes. Now, I will leave it to you to solve the question of preemption and whether or not the States would want you to do this.

I think you also have to keep in mind that any voluntary health organization operates through both its national organization and its chapters. The only fair way to equate it is with the combined or consolidated report. I have discovered there is a word of art in the accounting field, and that confuses me, but it deals with whether a report is consolidated or combined.

I would also point out to you that as far as the comments that have been made with regard to the bookkeeping and accounting procedures, the health council has its famous black book which you have there.

The institute of CPA's has its book which I understand will be published in June. The health council has a revised black book that is in the process of coming out, I understand, and there is a rather voluminous book written by an outstanding accountant who deals with voluntary health organizations, Mr. Mal Gross, which I tried to read, but, again I am not an accountant, and I became confused.

I would say it is not a question, as the Senator described it, of creative accounting; it is an attempt to meet the standards that are set by the health council, so that there is in fact full disclosures.

With one other comment I will leave you, and that is I think that the questions on professional judgment are best analogized with the work of this chamber. The Senate chamber has 100 members in it, and they rely on staff to tell them a great deal. I think it is only fair that any organization rely on professional people to advise them.

In the area of program services, what the needs are, what the requirements are, this voluntary health organization, the Epilepsy Foundation of America, and almost every other one I know has a well-rounded professional advisory board from all over the country, made up of leading people in the professions who do advise.

That board has been expanded recently to include people other than physicians, to include educators, nurses, people who deal with the problems of epilepsy on a different basis than even a neurologist would.

I would not want to dignify the testimony you received here earlier as to the statistics. As I think I told counsel and Mr. Johnson and

Miss Hoffman, one of my favorite books is "How To Lie With Statistics."

They are like everything else that you do. The output is no better than the input. You get out of it what you put into it, and that is true of statistics, depending on where you find them, what you do with them.

It is my judgment that the statistics used by EFA on the basis of its advice from its professional advisory board, made up of leading people in this area in the country, are accurate, and I think it is totally unfair to suddenly go to one or two sources and come up with another set of statistics.

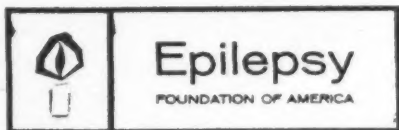
But I would leave that to you because I am quite sure that amongst professional people, just as amongst the hundred people of this chapter, there are differences of opinion. I do not think there has been a unanimous vote here in a long time.

Mr. KATZ. Thank you, Mr. Gordon. We will contact you with regards to future hearings.

The subcommittee hearing is adjourned.

[The subcommittee hearing was adjourned at 12:30 p.m., subject to the call of the Chair.]

[Appendix 1. - Material provided to the subcommittee by officials of the Epilepsy Foundation of America]



Suite 406 • 1628 L Street, N.W. • Washington, D. C. 20036 • (202) 783-2930
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Lawrence E. Schweitzer, Ph.D.

Public Information
George Wright, Ph.D.

June 13, 1974

The Honorable Walter F. Mondale
United States Senate
Washington, D. C.

Dear Senator Mondale:

Thank you for your letter of May 27 to which you attached a list of questions to which you would like answers in writing for the hearing Record. These answers are attached and, in accordance with your request, we have endeavored to answer as fully as possible and to provide supporting documentation where appropriate.

We wanted to respond to your questions as promptly as possible. Like you, I am concerned about several matters that were not brought out at the hearing. Hence, we are also going to accept your kind offer to put some additional relevant material into the Record -- some of which has been inspired by the questions you have asked us -- and we will prepare this and present it for inclusion in the Record as soon as we can get it ready in order to present a complete and balanced view of the Foundation and its operations.

We sincerely hope the material provided is what you had in mind, but should you have any questions, please do not hesitate to let us know. We remain anxious to cooperate with you in every way possible.

Cordially yours,

Paul E. Funk
PAUL E. FUNK
Executive Vice President

PEF:mjh

CC : Paul D. Holland, Esquire

Epilepsy--The more you know about it, the more you want to help.

[Committee Note: In the interest of economy all material submitted for the record could not be printed but may be found in the files of the Subcommittee.]

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EFA/SENATE SUBCOMMITTEE - 1
June 17, 1974

1. During 1972, what percentage of Don Organ's work time was spent on giving fund raising advice and assistance to EFA chapters, employees, and volunteers?
2. In what other activities did Organ engage in working for EFA during 1972?

Permit me to answer questions one and two together.

The authority given me by EFA bylaws states that I shall "coordinate the affiliate activities of the Foundation and its Affiliates (Chapters) and as such shall be responsible for assisting the Affiliates with their organizational, publicity, fund raising and other activities, assuring adherence by the Affiliates to the policies of the Foundation; organizing new Affiliates and otherwise promoting and maintaining an active Affiliate organization for the Foundation." I have delegated authority for these activities to Don L. Organ as head of the Community Services and Chapter Development Department, who filled that position during all of 1972 and still fills it. According to records, Mr. Organ's time was allocated in 1972 as follows:

Research	4.62%
Public Health Education	5.85%
Professional Education and Training	5.85%
Community Services	83.68%

Within the category "Community Services" time was spent giving fund raising advice and assistance to EFA chapters, chapter employees, and volunteers. Estimated at 10 percent of his time spent in this area within the "Community Services" category that would be approximately 8 percent of his total time.

Perhaps these services rendered on behalf of a chapter should have been attributed to fund raising per se instead of community services. From our reading of the National Health Council's standards, however, we interpreted this as community service rather than fund raising.

The demands and priorities of the chapter system obviously change throughout the period of a year depending largely upon the local needs of individual chapters, even though the basic assignment stated above is his function. Mr. Organ administrated five Regional Offices which were established to render community services through the development and continuing support of chapters.

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EFA/SENATE SUBCOMMITTEE - 2
June 17, 1974

1-2, 2-2

Mr. Organ's principal assignment was and is community services and chapter development for EFA. As one of our senior executives, he also gave staff services to a committee of the Professional Advisory Board. During the early part of 1972 he was involved in developing training programs for volunteers and professional staff which culminated in a regional meeting held in Denver and a national chapters workshop (a 3-day session attended by 300 people) held in Washington, D. C. In August Mr. Organ was assigned on an acting basis to the New York City chapter while the Board of Directors recruited a permanent Executive Director. For four months his activities were directed to helping that chapter on its way towards achieving a management structure and a comprehensive program serving persons with epilepsy. Mr. Organ helped the chapter implement some of its fund raising plans, but strictly speaking, these were services on the part of headquarters rendered to a chapter.

EFA/SENATE SUBCOMMITTEE - 3
June 17, 1974

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3. During 1972, what percentage of work time of EFA's regional managers was spent on giving fund raising advice and assistance to EFA chapters, employees, and volunteers?

.....

As authority is delegated to Mr. Organ, so it is delegated by him to the Regional Managers who coordinate affiliate activities and secure adherence to policies according to local needs and priorities. The Manager may serve the chapters in the region in the following ways: (Reference: Materials and Services Available through Regional Chapter Service Centers, dated April 15, 1974 and submitted to the Subcommittee in the original statement.)

Program Services

- 1) Review and Commentary on Chapter Grant Application
- 2) Preparation of Grant Application for Chapter
- 3) Introductions to State and Regional Governmental Officials
- 4) Local Adaptation of Program Working Guide
- 5) Agenda and Arrangements for Local PAB Meetings

Public Information and Education Services

- 1) Arranging Publicity for Local Event
- 2) Review and Evaluation of Local I & E Plan
- 3) Contacts with Local Radio and TV Stations and Newspapers
- 4) Updating SPOKESMAN Mailing List and other Chapter Mailing Lists

Professional Education and Training Services

- 1) Assistance with Local Meetings
- 2) Counsel and Advise on Professional Seminar and/or Workshop

Management/Administrative Services

- 1) Preparation of By-laws, Articles of Incorporation
- 2) Assistance on Financial Reports
- 3) Assistance on Preparing IRS Exemption
- 4) Management Audit of Chapter for Chapter Board and Officers
- 5) Evaluation of Chapter Board of Directors
- 6) Recruitment of Chapter Board Members
- 7) Updating Chapter Manual and/or Local Working Guides

EFA/SENATE SUBCOMMITTEE - 4
June 17, 1974

3-2

BEST COPY AVAILABLEFund Raising Services

- 1) Development of Chapter Fund Raising Plan
- 2) Review and Evaluation of Chapter Developed Fund Raising Plan
- 3) Preparation of Proposal and Presentation to Local Foundations and/or Major Donors
- 4) Assistance in Carrying Out Local Fund Raising Events

At least 85 percent of the Regional Managers' time is spent in carrying out the above-mentioned services which directly assist the chapter in carrying out its services to the community. Thus, the Regional Manager is administering a community service, and, again, according to National Health Council Standards, the act of administering a program service constitutes a program service. That has been our interpretation and our planning has been done accordingly.

Out of these 22 activities, we would estimate that our Regional Managers gave an estimated 5 to 10 percent of their work time to assist and advise chapters in those fund raising services mentioned above. We chose to categorize these activities as community services. In retrospect, perhaps they might have been categorized instead, as fund raising, particularly numbers 3 and 4 under the Fund Raising Services section, above. To date, Regional Managers have devoted little or no time to activities 3 and 4, and I am strongly urging them to become involved to a greater extent.

EFA/SENATE SUBCOMMITTEE - 5
June 17, 1974

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4. During 1972, EFA national sponsored several membership campaigns for local chapters. Identify each membership campaign conducted in 1972 and state its cost to EFA national in terms of both direct expenditures and total salaries of EFA employees who worked on the campaign.

.....

A diversified and involved constituency and the enlistment of the person with epilepsy in his own fight have long been goals of the Foundation. Headquarters has been encouraging chapters to build up their membership in order to communicate more effectively and to involve more individuals in the movement. Such a constituency is a resource for working volunteers and board members. An enlightened membership is able to give public support to the chapters' goals. With this goal in mind the headquarters has assisted chapters in building their constituency in more formal fashion, has developed materials, and various plans tailored to local needs. In 1972 headquarters did in fact work with six chapters at their request to build the membership through a mail appeal. The intent to recruit persons to help in the fight against epilepsy is demonstrated in the attached materials. Such mailings were worked out between headquarters staff, field staff, and individual chapters (sample copy attached).

<u>Chapter</u>	<u>Direct Cost</u>
Houston	\$ 2,255
Boston	12,954
Baltimore	2,449
Peoria	1,906
New Orleans	2,487
Jacksonville	3,020

In each case chapter staff and volunteers were responsible for local arrangements including counting and depositing the money. Chapters agreed to pay for the cost of each mailing. Miss Margaret Mary Paul and Miss Albertha Walker were the principal headquarters staff persons in charge of this activity. Time records were not then kept in sufficient detail for us to determine precisely the salary costs of this activity.

EPA/SENATE SUBCOMMITTEE - 6
June 17, 1974

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5. Under which expenditure category are the costs of the membership campaigns listed in the 1972 EPA financial statement?

• • • • •

The costs of the membership campaigns were not listed in any headquarters expenditure category in 1972. The cost of these efforts were obligations of the affiliates (chapters) and therefore, not an expense to the national office.

EFA/SENATE SUBCOMMITTEE - 7
June 17, 1974

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6. During January, February and most of March 1972, Paul Funk, James Shannon, Pam Tolson, Hugh Gage, Melba Gandy and David Krear each listed a portion of his or her salary under fund raising on EFA work sheets. In each case, explain why the salary was not listed under fund raising in subsequent pay periods.

EFA records pertaining to the above-named individuals show the following, representing percentage of time spent on fund raising for a three-month period:

	<u>% of Time</u>	<u>Proportionate Salary Cost</u>
Paul E. Funk	2.0%	\$1,149
James A. Shannon	9.6%	2,250
Pamela Tolson	20.9%	786
Hugh Gage	9.0%	1,122
Melba Gandy	3.0%	397
David Krear	10.3%	2,287

(For example, 20.9% of Pamela Tolson's salary during this period equals \$786.)

Insofar as we are presently able to determine--from records and from personal June 12 contact with the individuals concerned--it is believed that the fund-raising work consisted of the following:

Paul E. Funk - Personal contact with actual and potential donors and personal writing or editing of fund raising materials.

James A. Shannon - Reached by telephone on June 12; confirmed that his time devoted to fund raising in 1972 was "approximately 10% of the year" and stated that it consisted primarily of supervision of Margaret M. Paul and occasional contact with David Krear.

Pamela Tolson - Was General Shannon's secretary, and although we have been unable to reach her, it is logical to assume that the work consisted of secretarial and typing assignments.

Hugh Gage - Reached by telephone June 12; stated he believed the allocations were reasonably accurate and that the work--which took place when he was Manager, Correspondence--consisted of working with the Fund Raising Department on form letters going to foundations, social, civic and fraternal organizations and C & I campaigns (letters to major business firms).

EFA/SENATE SUBCOMMITTEE - 8
June 17, 1974

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6-2

Melba Gandy - We have been unable to contact, but it is believed that the allocation covers work done on preparing proposals (she then headed Program Activities) for funding by the Foundation.

David Krear - Contacted by phone June 12; indicated that (as Traffic Manager) he was involved with the printing of fund-raising materials, but that at no time was more than about one-third of his effort in this area; hence the allocation for this time period would seem to be reasonably correct. During 1972 about 33% of his time was spent on arrangements for a national chapter workshop and the balance was spent on Public Information and Education matters, which is the department in which he had his principal assignment. In October, 1972, he was transferred to the Fund Raising Department, and his time after completing certain I & E assignments was all spent on fund raising.

These salaries were not listed under fund raising in subsequent pay periods because the individuals involved did not undertake fund-raising projects in the subsequent pay periods.

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7. During three pay periods in February and March 1972, the salary of Margaret Paul was listed under patient services on EFA work sheets. On what project was Miss Paul working during this time?

.....

It is difficult to reconstruct more than two years later the activities of any staff member. The nature of Miss Paul's duties was such that it is perhaps possible she was working with the Patient Correspondence Room to develop stock letters and stock answers with regard to various EFA operations and policies, including those having to do with fund-raising policies, ways to set up wills, legacies and bequests, membership elements such as medical identification cards and identification bracelets for persons with epilepsy, and related matters.

A telephone check with Miss Paul on June 11, however, elicited the information that she knew of no activities undertaken by her which would properly be chargeable to this category.

In the absence of evidence to the contrary, it would appear that this is an accounting error.

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8. Thomas Ennis testified before the Subcommittee that he devoted 15-20% of his time to fund raising during 1972. Yet, none of Ennis' salary is listed under fund raising on 1972 EFA work sheets. Explain this apparent discrepancy.

As Mr. Ennis indicated in response to Senator Mondale's question relating to his responsibilities, his duties and assignments through the years have changed depending upon the needs of the Foundation. Not having the time sheets or cost allocation sheets before him at the time of his oral testimony, Mr. Ennis relied upon memory and his memory in this instance turns out to be faulty.

In answering that he thought he spent "in 1972 I would think probably - maybe 15% to 20%" of his time on fund raising, Mr. Ennis was incorrect. This time allocation concerning fund raising would more accurately refer to portions of the calendar year 1973. As Mr. Ennis testified, in 1973 (later in the year) he received a new assignment -- announced in a staff bulletin dated August 29, 1973 -- which made him more specifically responsible for EFA fund raising with a particular emphasis upon chapter fund raising (refer to Page 6-7 of EFA's submitted Statement to the Subcommittee on Children & Youth on April 5, 1974).

Thus, the discrepancy between the cost allocation sheets and the testimony would appear to be due to Mr. Ennis' recalling 1973 fund raising duties rather than 1972.

For the record, Accounting Department Allocation Sheets for 1972 indicate that Mr. Ennis' time was spent thusly:

Research	31%
Public Health Education	7%
Prof. Educ. & Training	30%
Community Service	<u>32%</u>
	100%

EFA/SENATE SUBCOMMITTEE - 11
June 17, 1974

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9. During 1972, only the salaries of direct mail employees were listed under fund raising on EFA work sheets for most pay periods. Was direct mail solicitation the only fund-raising activity conducted by EFA during those pay periods?

.....

Direct Mail fund raising was not the only fund raising activity conducted during these pay periods. However, it provided the bulk of EFA's income for 1972.

As listed on the attached sheet, in 1972 91.2% of income to EFA came from direct mail. Hence it follows that most of the time allocated to fund raising was the time of direct mail employees. A limited number of non-mail projects were undertaken in 1972; e.g., Special Gifts, Deferred Income, Memorials, and the basic development of a Commerce & Industry Program (to be implemented in 1973), etc.

Even within these categories of non-mail, the principle "tools" used to generate it were: Direct Mail. See sample letters attached.

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1972
NATIONAL HEADQUARTERS MAIL & NON-MAIL INCOME

TOTAL: \$ 3,226,332

Mail	\$ 2,942,733	91.20%
Affiliates	79,321	2.45%
Government Grants	7,941	.25%
Miscellaneous & Interest	<u>6,008</u>	<u>.19%</u>
	\$ 3,036,003	94.09%
Wills & Bequests	\$ 44,404	1.37%
Memorials	4,800	.15%
Social & Fraternal	3,758	.12%
Foundations	47,506	1.47%
Major Donors	37,991	1.18%
Funds, Restricted Gifts & Other	<u>51,870</u>	<u>1.62%</u>
Total Other	\$ 190,329	5.91%
Total	<u>\$ 3,226,332</u>	<u>100%</u>

FA/SENATE SUBCOMMITTEE - 12
June 17, 1974

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10. What is James Bradley's present position with EFA? What is his title?
What are his responsibilities? How much does he receive from the
EFA in salary? In expenses? Where is his office located?

Mr. Bradley currently is a volunteer, and as such he is the executive director of the New York State Division of EFA. As executive director for NYSD, he is in charge of the administration of the state organization. Since his office is combined with the Tri-state Chapter in Albany, as a volunteer he also is helping that chapter in its administration and its service program. Currently, he receives no salary from EFA headquarters. Currently, he receives no expenses from headquarters. The NYSD has rent and telephone expenses which are paid for out of its treasury. His office is currently located in Albany, shared with the Albany chapter, at 62 South Swan Street, Albany, New York 12210.

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EFA/SENATE SUBCOMMITTEE - 13
June 17, 1974

11. Does EFA invite bids on its contract work? If so, describe the procedures used in this regard.

We are not sure of the precise meaning of the term, "contract work." But if you mean how EFA National purchases goods and services, you will note that as a general rule, we solicit bids on purchases in excess of \$500.00. Attached is a copy of a page in EFA's Standard Operating Procedures Manual, dated April 5, 1971, outlining policy and procedure.

Also attached is an EFA Staff Directive, dated May 19, 1972, on Purchasing Routines, which makes clear the difference between preliminary negotiations to obtain tentative agreements on prices, specifications, etc., and actual commitments for the delivery of any goods or services. Although the department that requires the goods or services conducts the preliminary negotiations, commitment of monies must be by Purchase Order signed by the Director of Administration or his delegate.

As pertains to "contracts" as EFA defines them, see Standard Procedure No. 1019, dated December 3, 1973, attached.

Also attached is a standard EFA Estimate Form.

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Epilepsy
FOUNDATION OF AMERICA

FOR JOB REGISTER

EFFECTIVE
4/5/77

REV. NO.

APPROVED

Chief Executive Officer

I. PURPOSE

The purpose of this procedure is to set forth the policy of the Foundation regarding recording and monitoring all assignments within the Information and Education Department.

II. POLICY

The Foundation believes it desirable to centralize records pertaining to the work of the Information and Education Department in order to schedule assignments for on-time completion, to make clear which specific staff member is working on a project, to facilitate traffic expediting, and in order to have available a permanent record of all jobs and the cost pertaining to same.

III. PROCEDURE

The Director of Information and Education specifically delegates to the Manager, Education Services, the responsibility for "opening" a job requisition on all assignments accepted by the Department or originated within the Department (see form attached).

The Manager, Education Services, at his option, completely fills in this form or fills in key data and delegates to the Manager, Production and Scheduling the completion of all information items.

When sufficient information exists to begin work, the Manager, Production and Scheduling will enter the assignment into a job register maintained by him for this purpose (see form attached.) The format of the job register is the prerogative of the Information and Education Department but will, minimally, indicate the specific staff member handling a given project and the scheduled completion date.

The job register will be consulted by the Production Assistant in connection with the issuance of periodic status reports (see form attached), which will be distributed to all Department heads and the Chief Executive Officer no less often than every two weeks.

A copy of the job requisition referred to above will accompany the job folder as it moves from person to person throughout the Foundation toward completion.

After the job has been assigned to a staff member -- and while copy is being prepared -- the Manager, Production and Scheduling will obtain such cost estimates, paper samples, ink samples, construction dummies and other materials useful in arriving at a final production specification.

The estimate form to be used is the form attached. Estimates will be obtained in accordance with the following procedure:

- Items costing less than \$50 require no estimate;
- Items, the cost of which is estimated to run between \$50 and \$500 require a written estimate from the supplier or suppliers involved
- Jobs costing \$500 or more will require competitive bids from at least three supplier

In awarding jobs, due consideration will be given to quality and past experience. As a general rule, all jobs will be given to the bidder quoting the lowest price. The Director of Information and Education, however, with the concurrence of the Director of Administration and Finance, may award a job to a supplier other than the one submitting the lowest bid. In such instances, the files on the job will make clear the reason for departure from standard procedure.

EFA/SENATE SUBCOMMITTEE - 14
June 17, 1974

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12. Since Donald Gilbert ceased being an EFA employee in mid-1971, EFA has entered into several contracts with Gilbert and companies with which Gilbert is associated; contracts that involve payments and obligations that total more than \$250,000. Were bids solicited by EFA on these contracts? If so, describe how the bids were solicited and identify each bid received. If not, what procedures were used to determine that Gilbert and his companies were qualified to do the contract work and that their contract price was reasonable in each case?

.....

Insofar as I know, Donald Gilbert since leaving EFA has been an employee of Kaleidoscope Films, Ltd., 6345 Fountain Avenue, Hollywood, California, 90028. It would not be accurate to refer to "Gilbert and his companies."

Yes, bids were solicited on most jobs which subsequently were awarded to Interkal, a division of Kaleidoscope Films, Ltd. For example, attached are copies of letter bids which were solicited by EFA from Interkal, June 11, 1973, and from AVCO Film Productions, June 17, 1973. Only two letter bids were solicited in this instance because business discussions with other film producers indicated that their bids would be higher.

The Kaleidoscope bid was low. In addition, Mr. Gilbert was able to contribute in a unique way to the production of the films because of his personal involvement with and knowledge of the epilepsy movement. He understands the health field universe and specifically the complexities and interworkings of patients, doctors, nurses, educators and social workers as well as the medical, psychological and social problems faced by patients.

As an example, in regard to the "Centers of Excellence" film (see Kaleidoscope letter dated April 17, 1972, signed by Andrew J. Kuehn, Jr., copy attached), EFA was able to capitalize on the fact that the Kaleidoscope crew would be in Europe on an MGM assignment and, therefore, would be able to provide film footage that would not otherwise be available and that EFA, under normal financial strictures normally would not be able to afford. As is obvious from the enclosed material, when certain production functions could be obtained at a lesser cost or with greater efficiency than Kaleidoscope offered, those functions were assigned to other suppliers. (See copies attached.)

To respond to the question about Gilbert and his companies' qualifications (and again we would register the point that they are not his companies to our knowledge), Kaleidoscope are well known producers located in Hollywood. Mr. Andrew Kuehn and Mr. Donald Davis, who are owners of the firm, have done extensive work for such firms as Metro-Goldwyn-Mayer, Universal, Paramount, Columbia and a long list of responsible clients.

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<u>Date</u>	<u>Description</u>	<u>Amount</u>	<u>Other Contracts in Regard to Same Work</u>
1/24/72	Kal. Remake of 4 TV Spots	\$ 1,900.00	*Byron Motion Pictures 2/11/72
5/4/72	Kal. Centers of Excellence	15,000.00**	Capital Films
9/21/72	Kal. Centers of Excellence	13,000.00**	
10/1/73	Interkal 4 TV Spots	5,075.00	Modern Talking Picture
6/19/73	Interkal 3 - 28 min. films	137,500.00	AVCO
	6 - 10 min. films		
	4 - 30 sec. TV Spots		
5/3/74	Interkal 8 - 15 min. "shows" suitable for audio cassettes	4,800.00***	

*Also D.C. Film Printers (Bob Cooke, EFA, 9/1/71).

**As described earlier in answer to this question.

***Interkal did the recording at the same time as they were preparing film thus saving considerable money by using a doctor-participant for a dual purpose.

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13. In recommending that one of Gilbert's companies be awarded \$137,500 in contract film work, EFA's deputy director of information and education, Hugh Gage, rendered an expert opinion as "a former member of ASC" that Gilbert's prices were reasonable. Was Gage, in fact, an expert in cinematography when he made this recommendation? What was done by EFA to verify Gage's opinion on prices?

A misunderstanding persists that these are Gilbert's companies, but we have answered that.

In effect, the question distorts the process by which judgments were made concerning the production of creative material. Mr. Gage as an employee of the Foundation and the head of the Information & Education department was responsible to see that production of these films was implemented. His opinions and judgments were verified by many within the organization including the Chief Executive Officer.

As a matter of course he wrote to Mr. Gilliatt, member of EFA's national board, chairman of the Information & Education Committee and the vice chairman of the Interpublic Companies, one of the country's largest advertising and marketing agencies. Mr. Gage's letter and Mr. Gilliatt's reply are attached.

I do not know whether or not Hugh Gage is a former member of ASC, which I assume refers to the American Society of Cinematographers. In reviewing his resume, I find no reference to it.

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14. In several newsletter articles and in EFA annual reports, Hugh Gage is praised for work done as an EFA executive and for his academic accomplishments, being referred to either as "Dr. Hugh Gage" or "Hugh Gage, Ph.D." Had Gage, in fact, been awarded a doctorate degree? If so, when did he receive the degree and from which university? If not:
- (a) Upon what information were the references to Gage's academic credentials based?
 - (b) What is the total amount that the EFA has paid to Gage to date in salary, fees, fringe benefits and expense reimbursements?
 - (c) Identify each EFA contract (by date, contractor, nature of work and contract price) entered into upon Gage's initiations, recommendation or approval. Have all these contracts been reviewed by other EFA personnel to determine whether the work and prices are reasonable?
 - (d) Since Gage's hiring, has EFA changed any of its procedures regarding examination of a job applicant's academic and professional credentials? If so, how?

During his employment with EFA, Hugh Gage did indeed receive praise (and well warranted praise) for his work. Mr. Neal Gilliatt has written to Mr. Gage "...you were clearly the best Director of Information and Education we have had." However, I am unfamiliar with any praise for "his academic accomplishments." References as "Dr. Hugh Gage" or "Hugh Gage, Ph.D." are not normally considered "praise for academic accomplishments."

I do not know whether Gage has been awarded a doctorate degree. Such a credential was not needed for any of the work to which he was assigned with this Foundation, and we did not make special investigation into these qualifications when we hired him.

Questions (b) and (c) in regard to Mr. Gage's salary and reimbursements and in regard to EFA "contracts" entered into upon Mr. Gage's initiation or approval seem to be irrelevant here. Purchasing policies and procedures have been outlined previously in this statement. In fact, the structure of this question and the linking of unrelated matters might be construed as an indication that serious allegations have been made that Mr. Gage's employ, his actions as an employee, and the management of EFA are under suspicion of wrongdoing, or at least, ineptness.

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We feel sure that this was not the Subcommittee's intent, and would respectfully suggest that if any such feeling exists that EFA be given an opportunity to discuss and refute any such suspicions.

In spite of the irrelevance of questions (b) and (c), and in order that the Subcommittee record has full and complete information on every phase of EFA management and operations, the following material is furnished.

When we employed Mr. Gage on May 24, 1971, as Manager, Production and Purchasing in the Public Information and Education Department, we checked to see that his resume, and his own statements to us, amply documented qualifications and experience pertinent to that position.

Mr. Gage was hired in accordance with a procedure dated November 15, 1971, a copy of which is enclosed. You will note that it calls for reference checks (which were made) and a background check. That background check was made by Retail Credit Corporation and it referred to him as "Dr. Gage."

Hugh Gage began using the designation "Ph.D." on or about March 1973 at which time he was questioned by General James A. Shannon as to whether he indeed possessed that degree and he replied in the affirmative. If in fact he did not possess same this is most unfortunate for it was by no means required for the work he was doing. We accepted his statement, and we permitted Gage to so designate himself. Later on, when he acknowledged that he had misrepresented his academic status, he left EFA immediately.

Since Gage's hiring EFA has not changed any of its procedures regarding examination of an applicant's academic and professional credentials. It is in the process of doing so, not as a result of our experience with Gage, but rather because of new and evolving legal requirements and standards relating to personnel.

The assignments and the salaries paid Gage in each are summarized in the table below:

		<u>Annual Salary</u>
5/25/71	Manager, Production and Purchasing Information and Education Dept.	\$10,400.00
1/25/72	Manager, Correspondence	12,100.00
1/19/73	Manager, Correspondence	12,961.00
3/30/73	Manager, Correspondence	13,771.00
4/27/73	Deputy Director, I & E	16,395.00
10/12/73	Deputy Director, I & E	18,401.00

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These totalled \$33,485 for the period he was with us and fringe benefits (approximately 15% of salary) totalled \$5,022 and covered group and life and health insurance, retirement, social security, and annual and sick leave. Expenses incurred by him during his tenure which were reimbursed by the Foundation totalled \$2,434.

Mr. Gage had no authority to enter into contracts. By Board resolutions all contracts must be authorized by the Chief Executive after review by Legal Counsel. Mr. Gage was involved in the purchasing process and indeed during his tenure as Manager, Production and Purchasing, was involved with initiation, recommendation and approval of virtually all items purchased by the Foundation. That list -- if needed -- will require several weeks to prepare.

During his tenure as Deputy Director, Public Information and Education, he was responsible for 95 purchase orders, a list of which is attached.

Purchasing routines followed by the Foundation are outlined in detail in procedure on Job Register dated April 5, 1971 and utilize the following forms:

1. Job Requisition
2. Job Jacket
3. Estimate Form
4. Purchase Orders

Our routine is such that each of these is prepared by the Manager, Purchasing and Production (who during that period and up until the present is Mr. Xope Hyman) and approval initials from the department head involved, the Controller, and signed by the Deputy Director, Administration and Finance. In short, all these purchase orders have indeed been reviewed by other EFA personnel to determine whether work and prices are reasonable . . . and whether or not in accord with Board approved budgets.

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15. Several years ago, the EFA board of directors resolved that top priority should be give the organization's public health education program. State the name and title of each EFA employee who has directed this program from January 1971 through the present, and the dates during which each such employee was responsible for directing the program. What percentage of EFA funds has been devoted to this program in each of the years 1971, 1972 and 1973?

Both EFA practice and Foundation's By-Laws designate the Chief Executive Officer as the chief spokesman for the organization. As such, I am and have been personally in charge of Public Education and Information during the entire period referred to. Major assistants in discharging these responsibilities have included the following:

<u>Name</u>	<u>Title</u>	<u>Dates</u>
William N. Brown	Mgr.-Education Services	March, 1971 to February, 1972
Joseph J. Rizzo	Deputy Director	February, 1972 to November, 1972
Hugh H. Gage	Deputy Director	April, 1973 to November, 1973
James E. Gorman	Associate Executive Director	February, 1974 to Present

Note: During the period from January, 1973 thru April, 1973 Robert Hayden Jones Associates, Westport, Connecticut provided the services of Robert Hayden Jones as consultant. He also performed the function of Deputy Director, Information and Education, but was not an employee.

Public health education is indeed the number one priority of EFA. This involves many supportive activities. For example: school and teacher education programs; educational and informational programs for family health medical doctors, nurses, paramedical personnel, psychologists, social workers, employers, union leaders and vocational rehabilitation specialists.

Percentage of total expenditures for public health information in 1971 and 1972 based on figures in the annual reports for those years audited by Price Waterhouse are as follows. Audited figures for 1973 are not available but preliminary figures are as follows:

	<u>EFA Total Expenditures</u>	<u>I & E Total Expenditures</u>	<u>Headquarters Only %</u>	<u>Headquarters & Chapters combined %</u>
1971	2,680,592	246,365	9.2	9.0
1972	3,157,878	245,738	7.7	7.7
1973	3,597,352	351,585	9.8	9.8

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16. Since 1969, EFA annual reports have stated that the organization is developing fund-raising programs other than direct mail solicitation. Describe each such program and state the name and title of each EFA employee directing each of these programs since 1969, and the dates during which the employee directed the program.

Upon the founding of EFA one of the goals of the EFA Board of Directors was to, as rapidly as possible, become less dependent upon direct mail as the main source of revenue.

In an effort to begin a national non-mail program, Mr. John J. Leonard was hired in June, 1968, to serve as EFA's Director of Development & Resources. Mr. Leonard, an experienced fund raiser, directed this activity while located in New York City.

Mr. Leonard's first assignment was to develop a National Commerce & Industry solicitation and a Special Gifts Program. Shortly after joining the EFA staff Mr. Leonard became seriously ill and died on July 13, 1969.

From the time of Jack Leonard's death in July, 1969, to March, 1971, there was no EFA staff person directing this non-mail sector. During this time Mr. Thomas M. Ennis, as Executive Director of EFA, was responsible for over-view functions, with the assistance, for portions of this time, of two staff members. During Mr. Leonard's illness Mr. John Jefferson and Mr. Ted Earle were hired in mid-1969 to assist with this non-mail activity.

Within this time frame segments of a limited national Commerce & Industry were developed, certain special gifts solicited and basic development for chapter fund raising material was designed.

In March of 1971 Mr. George M. Gillet was hired as Director of Development (time of employment: 3-71 to 1-72), to develop these non-mail sources of income, including Commerce & Industry, Foundation support and Special Gifts. Mr. Gillet was released from his position in 1972 due to dissatisfaction with the results of his efforts.

During Mr. Gillet's tenure he was assisted by two other staff members, Mr. Ted Earle and Mr. Robert Swartzel.

In 1972 Mr. Joseph Rizzo, who had received his indoctrination into EFA as Director of EFA's Information & Education Department, became Deputy Director of Fund Raising. (Time of employment: 2-72 to 1-73; Fund Raising assignment: 8-72 to 1-73)

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While Deputy Director for Fund Raising, Mr. Rizzo was largely involved in Direct Mail Supervision and started to develop limited non-mail sources of support (still largely involving the use of Direct Mail; e.g., Special Gift letters). It was felt that Mr. Rizzo's background in Information & Education would greatly accelerate the development of fund raising material and kits.

In late 1972 (11-72) Mr. William Sutherland joined EFA as Director of Development and assisted Mr. Rizzo with Direct Mail supervision and became involved in developing non-mail sources of support (again using mail as the primary means of reaching donors). Mr. Sutherland took over Mr. Rizzo's duties as Deputy Director of Fund Raising (Time of employment: 11-72 to 5-74).

By 1973 Mr. Sutherland's duties involved some direct mail supervision, Development of Commerce & Industry, Special Gifts, Chapter Fund Raising and Foundations. In mid-year (1973) Mr. Sutherland began to concentrate on Chapter Fund Raising.

In 1974 Mr. Sutherland continued to have duties in the development of Commerce & Industry, Special Gifts, Chapter Fund Raising, and preparations of Chapter Fund Raising material.

As of late 1973, Mr. Thomas M. Ennis, Executive Director, was assigned specific responsibility for direction of EFA Fund Raising. Prior to this fund raising assignment Mr. Ennis was largely involved in Professional Advisory Board activities, Professional Education and Training, Community Services and Public Health Education.

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17. In his testimony before the Subcommittee, Paul Funk repeatedly referred to EFA's 164 chapters. Are all these chapters fully operational? If not, how many are fully operational?

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There are currently 164 chapters, four more than was reported as of the end of last year. We also have one cooperating organization, giving us a total of 165. The number 164 refers to the number of chapters or local organizations which are functioning to carry out the purposes of the Foundation. Some local organizations are classified as "full affiliates" of the Foundation. They achieve this status by meeting affiliation requirements. Others are classified as "provisional" chapters. The standards they are required to meet are less demanding and this group is working toward full affiliate status. Still others are in the rudimentary stage of organization and these are called "Information Contacts." The requirements here are minimal and no formal agreement is involved. Some of the affiliated chapters have organized sub-chapters or local units to better serve their communities. The current break-down is according to the box below:

Affiliates	80
Sub-Chapters of Affiliates	4
Provisionals	25
Information Contacts	<u>55</u>

164

The chapters categories above are all operating units of the Foundation. Obviously some are more effective than others in reaching the goals of their respective categories. Some chapters have been phased in during the last twelve months, some have been down-graded, reflecting weaknesses. Some have been accorded affiliate status.

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Epilepsy Foundation of AmericaThe Cost of Putting One Solicitation Piece in The Mail1973 - Mailing to Our Own House List

Average - \$48 per M	.0170 Postage
	.0061 Seals
	.0036 Letter
	.0090 Envelope
	.0049 Reply Envelope
	.0074 Assembling (Lettershop)
	<u>.0004 Computer Service</u>

\$.0484

1973 - Mailing to An Outside List - Prospect

Average - \$72 per M	.0170 Postage
	.0061 Seals
	.0036 Letter
	.0090 Envelope
	.0049 Reply Envelope
	.0084 Assembling (Lettershop)
	.0100 Penny
	.0130 Name Rental & Exchange
	<u>.0002 Computer Service</u>

\$.0720

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[Appendix 2. - Consultant's Report on Epilepsy Foundation of America]

July 12, 1974

TO: Senator Walter F. Mondale
Chairman
Subcommittee on Children and Youth

FROM: Harvey Katz, Consultant

Consultant's Report on Epilepsy Foundation of America

Several weeks ago, you directed me to investigate several matters concerning the Epilepsy Foundation of America (EFA) that were raised during Subcommittee hearings on the organization or by investigations conducted by myself and Subcommittee staff. I have examined EFA testimony during the hearings, replies to questions you propounded to EFA after the hearings, EFA financial and other records; interviewed former EFA employees; and conducted other inquiries into these matters.

Misrepresentation of Fund-Raising Costs

As you know, EFA representatives were unable to produce any records during the hearings to justify allocation of only \$52,000 in EFA salaries to 1972 fund raising. After the hearings ended, these sheets were submitted to the Subcommittee. The sheets contain several pieces of information worth noting:

(1) None of the salary of Thomas Ennis, EFA executive director, was allocated to fund raising during 1972, even though Ennis testified at the hearings that 15-20% of his time was spent on fund raising during 1972 (in reply to your written question on this point, EFA has stated that Ennis' testimony--not the allocation sheets--was erroneous);

(2) During one month in 1972, the salaries of two people working exclusively in fund raising were listed under other categories (EFA says this was an accounting error);

(3) During 1972, none of the EFA employees who render fund-raising assistance to chapters listed their salaries under fund raising (in reply to your question on this point, EFA estimates that 5-10% of these salaries, which total \$260,000, was spent on fund raising, but interviews with several EFA board member, chapter personnel and employees have convinced me that this figure should be 50%, or \$130,000 in 1972);

(4) In January and February, 1972, four top EFA executives--Paul Funk, James Shannon, Melba Gandy and Hugh Gage--who were not part of the EFA direct-mail department, listed some of their salaries under fund raising; but they did not do so during the remainder of 1972 (in reply to your question on this point, EFA says that their salaries were not so listed for ten months of the year because they were not involved in fund raising then; but EFA also claims that it was carrying on a significant non-direct-mail fund-raising effort during all of 1972).

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- 2 - 3 -

For the above reasons, I have concluded that EFA fund-raising costs for 1972 were grossly under-stated on its financial statement. I base this conclusion on statements by several EFA employees who told me that four to six key EFA executives (including Thomas Ennis) spent considerable time on fund raising in 1972 and that the major activity of EFA field offices was fund raising; and on the accounting errors, faulty recollections, lost records and unconvincing explanations that EFA has revealed to the Subcommittee on this question. While it is impossible for me to reach a definite figure on the amount of the under-statement, I estimate that fund raising cost the organization at least \$330,000 more than shown on its financial statement (\$50,000 in national salaries and overhead, \$130,000 in field office salaries, and \$150,000 in field office overhead, mostly travel).

Since the 1972 EFA financial statement, including the amount of fund-raising costs, is certified by Price Waterhouse, I met with two representatives of that auditing firm to determine whether their certification or my conclusions should be given greater credence. The representatives told me that they had simply accepted the figures of the EFA as to how employees spent their time and that they had done little, if anything, to verify expenditure allocations generally. They admitted that this was their responsibility and that they had revised their auditing procedures as a result of what had been brought out during the Subcommittee hearings.

Observations and Conclusions

Evidence obtained through hearings, written questions and examination of EFA records clearly establishes that this organization has fallen considerably short of the ideal in regards to fund raising and other management activity. Records that should have been readily available were not available and then suddenly popped up accidentally. The organization was claiming a massive effort to reduce its fund-raising costs and develop non-direct-mail programs, while listing the salaries of only three employees under "fund raising," all of them exclusively involved in direct mail. There was nearly a 100% employee turnover while EFA was claiming to be making great strides in all areas.

I believe that most of the people involved in EFA are very well-intentioned. Testimony during the hearings demonstrated, however, not all of them--probably very few of them--have taken any interest in management details or in how contributions are being spent. There is also the obvious tendency to blame the unpopularity of the epilepsy cause for EFA's problems rather than mismanagement. Finally, we have seen repeated demonstrations of EFA's lack of forthrightness with the Subcommittee, the contributing public and perhaps even itself (if you can explain away or disguise a problem, you don't have to face it and solve it);

Had EFA been subject to an effective federal disclosure law for the past few years, I believe it would have taken a more effective approach to its problems and would now be doing a much better job of serving the people who need its help.

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[Appendix 3. -- Additional material provided to the subcommittee by the
Epilepsy Foundation of America]



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Rehabilitation

George Wright, Ph.D.

April 5, 1974

The Honorable Walter F. Mondale
United States Senate
Washington, D.C. 20510

Dear Senator Mondale:

When you first wrote to me under date of April 1, I forwarded copies of your letter to all of our 164 local chapters and to all members of our national Board of Directors and national Professional Advisory Board inquiring of these constituencies what information they would like to see included in the Foundation's prepared statement. These have been incorporated into the material being delivered to your office today.

A letter from one of our chapters -- the Copper Chapter of Great Falls, Montana -- did not arrive in time, however, and Mary E. Miller, the president of that organization, was particularly anxious that it be delivered to you.

I therefore hasten to send it along.

Cordially yours,

Paul E. Funk
Paul E. Funk
Executive Vice President

PEF/smv
Enclosure
cc: Mary E. Miller

38-970 208

Epilepsy--The more you know about it, the more you want to help.

(749)



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COPPER CHAPTER

Mary Miller, President
Virginia Pedro, Secretary
Lee Zadick, Treasurer
W. A. Richards, Chairman,
Board of Directors

2317 THIRD AVENUE SOUTH
GREAT FALLS, MONTANA

March 30, 1974

Mr. Paul Funk
Executive Vice-President
Epilepsy Foundation of America
Washington, D.C.

Dear Paul,

In reply to your letter of March 27, 1974 we of the Copper Chapter would like to submit the enclosed summary of our programs and also what we would like to have submitted to Senator Walter Mondale and his Subcommittee regarding the hearing taking place on the 8 & 9th of April.

We are hoping to impress upon the committee that while we are new and have not gotten into the core of the problems of epilepsy in Montana there are many and there is a lot of work to be done in our own city, and the geographical area which our Chapter will be headquarters in regards to other cities and communities. I am sure unless you have been in Montana or any of the people who will be at this hearing to visualize the distances of miles involved in north central and western Montana. We are an optimistic bunch of Montanans and are determined to do a job that is justifiable to our fellow Montanans, and we are in there with our sleeves rolled up and ready to go to work.

We will be most anxious to hear the outcome of the hearing, and until the next time we remain sincerely yours,

Copper Chapter of Epilepsy

Mary C. Miller
Mary C. Miller --- Pres.

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Senate Subcommittee Hearings:

Attention; Senator Walter F. Mondale, Chairman

The Copper Chapter of Epilepsy of Great Falls, Montana, do hereby request the committee to seriously consider the following to be put into the form of a Congressional Bill to be presented to the House of Representatives and sent onto the Senate committee of Health, Welfare and Education also to compile a bill to presented on the Senate Floor for a hearing and vote, which can become law with the Signature of the President.

1: Allocate funds through the H.S.W. Office to be used for the express purpose of instilling throughout each State, whereby all Schools will require a Health Related Program through their Health Personnell at the beginning of each school term to educate Teachers, Nurses, Counselors or other personnell and alert to the proper symptoms of Epilepsy and other Healthe-Related problems. To insure through such a program that no child shall be denied his education because of ignorance or prejudice on the part of any School Personnell.

2: Through the allocation of funds to Health Programs a specified amount of monies be set aside for Grants to Chapters who are just getting organized and meet the necessary requirements of the Federal and State Governments, when all requirements are met, a Grant can be applied to help operate the Chapter on a Two-Year Basis, without a Mandatory matching Fund. A new Chapter shall submit a Budget complete compiled by a Qualified Licensed Practising Certified Public Accountant and approved by the Board of Directors. Allocation of monies on a priority basis with no more than one-fourth to cover administrative costs and the Balance to programs related to Medical, Social and Recreational, Educational assistance directly to or indirectly to children and adults alike. That any misrepresentation or ^{Misrepresentation} ~~misrepresentation~~ of said Grant shall be cancelled and recalled by the Government.

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We are not asking for the full support of a Chapter but only a subsidy after which a Chapter shall be capable of being in a position to raise most of the necessary monies to fill their needs. But it is often a hard task to get money in the community until such time it is proven to be a going concern and doing the job it has laid down. As in our case and probably many more the lesser populated states do not have as many available sources to raise enough money within a one or two year period and often times it is a struggle for many to survive. This is our thoughts on it. we will have fund-raising programs and do hope that within a two year period we will be on a firm foundation financially with request for Federal monies for specific programs.

Summary of Planned Programs

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At the present time the Copper Chapter of Epilepsy of Great Falls, Montana an affiliate of the Epilepsy Foundation of America is registered with the Secretary of Montana, Helena, is the only Non-Profit Organization in North Central and Western Montana to deal with the individual and community problems directly related to the Epilepsies. We are a new Chapter having been founded less than a year and are just beginning to realize the problems facing the Epileptic and his family. Our current and most pressing project at this time is setting up and Information and Referral Service office, which was supplemented with a Grant from the D.D.S.A. and will enable to be initially on an operating basis by the 15 of April. In conjunction with the opening of this office the following are the goals of the Chapter and our long range plan of programs.

POPULATION TO BE SERVED;

It is estimated that there may be as many as 100,000 Montans afflicted with one form of epilepsy or another. While there are no comprehensive statistics at the present time, we are planning a determined effort to compile a count to as near as accurate as possible record to determine the known number of diagnosed within the portion of the State we will service. This will be done through Health and Medical Facilities without violation of privileged information and no names listed, nor will there be at anytime a name asked for, just a number from their sources.

MEDICAL FACILITIES:

A survey will be taken to seek out the Major Hospitals available with proper diagnostic and treatment facilities, these are no doubt in the larger cities of Montana. With an accurate listing of these, it will be easier for us to give assistance through referral the full utilization of these and the access necessary to gain them.

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SURVEY AND ANALYSIS OF MEDICAL FACILITIES:

While we can readily ascertain the facilities available in the hospitals, there is no known survey of the qualified physicians and nurses available to the epileptics. Thus to have a successful information referral service we deem it necessary to have the aforementioned and this survey completed and on file to assist the epileptics.

EDUCATION:

While we still are a new organization we fully realize the need for education of epilepsy is of the utmost importance in our program. The lack of knowledge in our own community makes us wonder the how much less known is known in the other communities. Many Medical doctors are lacking in knowledge of diagnosis or treatment of epilepsy. An example is the Petit Mal which may go undetected for several years under the untrained eyes of the parents or the teachers with whom the child spends the major share of his time. Only through education will they be able to detect the symptoms and bring it to the attention of School Health Personnel, who then can carry through with the child being properly diagnosed and treated with proper medication, by a trained Medical Doctor.

POLICE--FIRE--AMBULANCE

Usually when a person will have a seizure of Grand Mal the police, Fire or Ambulance are called to the scene. Along with other law enforcement agencies, this is an area which needs a very definite and acute awareness to recognize a seizure. Needless to say that through their lack of knowledge and ignorance of epileptics, too often the person may be jailed as drunk, mistaken for other medical disorders and result in an un-needed medical expenses. Therefore we are going to have a full fledged program aimed at all law enforcement including the officer in a patrol car, the highway patrol, the sheriff's Dept, Ambulance Services, and the on the premise of jails, juvenile halls and prisons started through and educational program.

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SOCIAL AND RECREATIONAL:

Like many other communities across the nation it is sad but true that in Montana there those who carry prejudices into the social and recreational activities which are geared to the children, teenager and the adult. It is definitely due to myths and ignorance carried down from generation to generation that the epileptic is different and should not be associated with, whether it be in school, or away from school.

Due to these misinformations it is necessary to have recreational activities that the children and the parents can participate in to give them the knowledge that there are others like them. Once they can be fully convinced of the importance of their medication towards control of their seizures, then will they become aware that they too can lead as normal a life as anyone else and be able to cope with day to day living. Our Chapter will strive for the activities that are viable in the community and with the help of volunteers implement those programs that are not.

EMPLOYMENT:

While the Chapter will through Education, counseling and social programs help to alleviate many of the problems, there is still the most important prejudice to overcome which is employment. In order for the epileptic attain a normal life and be a self-supporting and asset to his community he must have the dignity of every man's right to be self-supporting through employment. This will entail seeking out the private and State employment agencies in education and their knowledge will in turn be valuable in overcoming the prejudices held by both the employer and the employee, with Vocational Guidance to help insure he is employed in a field which is not a hindrance to him as most controlled Epileptics are employable, but usually are more reliable and do his job in all capabilities better than the non-handicapped employee.

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In order to attain the goals and achievements we have set down for our Chapter it was necessary to begin with a realistic budget that will insure us the results we hope to see as the years go by. Our first of course will teach us many ways to do better each year and also be an incentive to even set higher goals for the Epileptic and his family.

The Board of Directors met and with a very sincere desire to put the programs on their right priorities estimating the cost of each. It was then given to our Board Member, Mr. Dick Peterson a Certified public accountant to set up a realistic budget allowing a 5% for any future inflation which may arise. The Board voted the most important was the Information and Referral Office to be Staffed with an Office Manager and one full time Field Director for an overall program. Education rated next and so down the line each program in its proper place. In order to do justice to all programs and taking into consideration the geographical area we will service a realistic figure of \$40,000.00 was arrived at, with less than 1/4 of this allocated to salaries and administrative costs.

On a separate sheet I shall put down some thoughts we have for the subcommittee which we hope will be given some very serious consideration and thought.

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MEMBER NATIONAL HEALTH COUNCIL

HONORARY NATIONAL
CHAIRMAN

JOEL LAMMAN

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Anthony Arango, Ph.D.Bio-Statistics and
Epidemiology
Leonard Chason, Jr., D.Sc.Psychology
George Galvin, Ph.D.
Lawrence E. Schwenger, Ph.D.Rehabilitation
George Wright, Ph.D.

FURTHER STATEMENT

SUBMITTED TO

THE SUBCOMMITTEE ON CHILDREN AND YOUTH

OF

THE U.S. SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE

APRIL 19, 1974

BY

PAUL E. FUNK
EXECUTIVE VICE PRESIDENT

-00000-

CONTENTS IN BRIEF

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3. Incidence, Prevalence and Other Significant Data on Professional Questions
4. EFA Literature and Studies.
5. EFA's Greater New York Chapter.
6. Regulatory Agencies in the States of Pennsylvania and North Carolina.
7. Problems Involved in Reducing Fund Raising Cost Ratios by Diversifying Activities and Transferring Fund Raising to the Local Level.
8. Comments by EFA Donors.
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10. Citizen Volunteers Need Protection -- and Appreciation -- as Well as Beneficiaries and Contributors.
11. Attachments and Additional Bibliography.

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Epilepsy—The more you know about it, the more you want to help

1. THE HEARINGS TO DATE AND SOME COMMENTS
IN REGARD TO REFERENCES CONTAINED IN
OUR ORIGINAL STATEMENT SUBMITTED APRIL 5

Having completed two days of testimony before the Subcommittee on Children and Youth, EFA continues to believe that only a careful reading of all of the testimony provided by the Foundation will enable the Subcommittee to arrive at a full understanding of the various aspects of Foundation activities that have been under discussion. With this in mind, we have provided a massive amount of information:

We have provided full and open disclosure of our management practices;

We made specific recommendations with regard to new fund raising standards and to more detailed, uniform financial reports for all jurisdictions; and

We have illuminated the citizen-volunteer network across the country working on a major problem on behalf of the nation and the progress and accomplishments of EFA.

Everything we were requested to bring has been supplied -- even including certain allocation worksheets for the year 1972 which we originally believed were not retained past completion and certification of the 1972 audit. I directed that these be promptly turned over to the Subcommittee as soon as they were located.

In correspondence with the Chairman prior to April 5, and in staff discussions with Subcommittee members, and by phone the day before the hearings, EFA endeavored to determine in specific fashion the subjects on which information was desired. We have extended full cooperation to the Subcommittee as best we know how. We would have had other documents with us on April 8 and 9 had we known what the Chairman wished to have us bring. For our files are voluminous.

So, too, was our original statement and perhaps its very length motivated against complete understanding of a very complex problem. The statement contained not only a great deal of information, but also a great number of references to other documents equally voluminous. Despite which, we believe they belong in the Record. We make reference to some of those again here in the belief that reference to them will clarify many questions. We have particular reference to the following:

- a. "Looking at Volunteers" article, March issue NATIONAL SPOKESMAN
- b. "EFA Bylaws and Board Committee Practices" document
- c. "Pfd Bylaws and Guidelines" document

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- d. "EFA Staff" document
- e. "EFA Affiliation Agreement"
- f. "What's Your Opinion?" poll form
- g. "1974 Operating Budget" document
- h. "Staff Monthly Reports"
- i. "1974 Chapter Fund Raising Plans" document
- j. "Price List - Materials and Services Available Through Regional Chapter Service Centers"

Over and beyond the above EFA will also be happy to make freely available Board and Professional Advisory Board minutes including Executive Committee and other Committee reports. These records of the labors of unpaid citizen-volunteers speak for themselves as to the dedication and stewardship exercised on behalf of our constituencies by the governing, the advisory and the implementing bodies of EFA.

The Foundation was, and is, concerned with the publicity following the April 8 and 9 sessions.

If I may, I would like to read into the Record at this time a portion of the letter sent to the Subcommittee under date of January 10, 1974, by our legal counsel, Gordon and Healy:

"... I feel it appropriate to spell out my apprehensions regarding this matter and your responses thereto.

"As you know, I had previously met with the above persons and Mr. Katz. He was not unknown to me at that time. He is the author of several articles which have been published in local magazines and, I understand, is a member of the bar.

"Mr. Katz is also the author of a forthcoming book to be published by Doubleday and Co. dealing with charities. I indicated to you my concern with regard to the juxtaposition in time, place and circumstances of his study for the committee and publication of his book at about the same time. I view with apprehension the potential advertising and promotion that might be carried on by the publisher denominating the author as a Senate investigator on the same subject. This would, in my opinion, throw the cloak of Senatorial approval around the author and the book.

"We also discussed my fears regarding the fact that Mr. Katz has made the Foundation itself one of the subjects of his forthcoming book. The question I raised with you was whether, having taken

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a position regarding the Foundation and its activities, Mr. Katz will be able to use his position at, and the power of, the committee to support conclusions he has already reached.

"You recognize that retractions and apologies never really correct erroneous statements and a group that depends on the public for support could be injured.

"With regard to this, you indicated that Mr. Katz would not be able to utilize his position to make judgment values on any information he obtains from books and records of the Foundation, but that you alone would personally review his work and exercise the appropriate judgment factors.

"We also discussed the question of whether or not Mr. Katz would utilize any information he gained in his official capacity regarding our client in work other than for the sub-committee. You advised that Mr. Katz had agreed prior to his employment by the sub-committee not to utilize information so obtained in any manner in connection with his current writing, future revisions of his book or any publication other than proper Senatorial business.

"You agreed with my fears that the mere mention of the name of a charity in connection with a Senate investigation, unfortunately carries with it, in this day and age, the possible implication of wrongdoing and that because of this you would personally review the work of the staff before any information is made public.

"You indicated that you were personally in favor of private charities and that there was no intention on your part or on that of your staff's to do damage to any charity unless you found actual evidence of wrongdoing. You indicated further that the purpose of the study was to review the possibility of setting uniform accounting standards on a national basis and I suggested there might be additional work done in the area of uniform reports to either a single source or to the various states on a uniform basis.

"I am sure that my conversation with you indicated to you my concern about the harm that might befall the Foundation by its mere inclusion in the investigation, but since you assured me that you will personally exercise essential judgment factors and final review, my fears have been somewhat allayed. I would suggest that you have Mr. Katz contact me to make arrangements to inspect the books and as I told you, I will be present at that time.

"On behalf of the Foundation, I would like to reiterate that the Foundation will cooperate wholeheartedly with you and the sub-committee in this matter."

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We know that the Chairman tried to be fair in the hearings. So, too, did the hardworking gentlemen of the press. And yet our fears, unfortunately, have been amply justified. In the April 22 issue of TIME Magazine, for example, we learn that "more than half of the \$4 million the E.F.A. spent last year went to meet fund-raising and administrative costs." As you know, we do not believe that statement to be true and have written TIME accordingly.

The item goes on to talk about "to correct such abuses" and to speculate that it may become necessary to require charitable groups to adopt uniform accounting procedures. Uniform accounting procedures are already in existence. Moreover, EFA made recommendations in its original statement in regard to how to further tighten same.

An article in the April 14 issue of PARADE gives us further concern. It refers to Mr. Harvey Katz and quotes a forthcoming book on "charity fraud". I will discuss this with PARADE's publisher, Dan Kinley, a fine honorable and good man and a long-time associate and friend of mine.

Other press coverage has reflected statements made in the hearings which are open to question. If these gain sufficient circulation, incalculable damage will be done to 4,000,000 Americans with epilepsy and to other millions of their family members. Our headquarters and some of our chapters across the country are already receiving phone calls putting doubt and apprehension into the hearts of citizen-volunteers attempting to improve the lot of their fellow man. This is a grave matter and the Epilepsy Foundation of America views it gravely. Among other things, it may make even more difficult our efforts to reduce fund-raising costs.

2. COMMITTEES, ACTIVITIES AND PROCEDURES OF AN ALL-VOLUNTEER
BOARD OF DIRECTORS AND AN ALL-VOLUNTEER
PROFESSIONAL ADVISORY BOARD

In order that it may now be made clear the mechanisms and the people with overview responsibility for national EFA activities, the chairmen of various committees are listed below. The responsibilities of the committees are detailed in the documents referred to in b, c and d in Section 1.

Chairmen of Board of Directors Committees

Thomas A. O'Neil, Esq., CPA
Finance Committee

David D. Daly, M.D.
Program & Long Range Planning Committee

Neal Gilliatt
Information and Education Committee

James MacDonald Watson, M.D.
Chapters Committee

Gene L. Pulliam
Fund Raising Committee

Robert M. Green, Esquire
Legal Committee

Frank Risch, Ph.D.
Vocational Rehabilitation Committee

Thomas E. Jenks
Nominating Committee

Ellen R. Grass
International Relations Committee
GLC Joint Committee

A. B. Baker, M.D.
Government Affairs Committee

Chairmen of Professional Advisory Board Committees

Adolph L. Saks, M.D.
Executive Committee

Alex J. Arieff, M.D.
Medical-Legal and Insurance Committee

Sidney S. Carter, M.D.
Research, Fellowships and Training Grants Committee

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Robert B. Aird, M.D.
Fellowships and Training Grants Subcommittee

Herbert R. Karp, M.D.
Training Grants for Paramedical Personnel Subcommittee

Fernando Torres, M.D.
Publications Committee

Melvin D. Yahr, M.D.
Membership Committee

Desmond S. O'Doherty, M.D.
Inquiries, Referral and Information Center (Library) Committee

Jerome K. Merlis, M.D.
Information Center (Library) Subcommittee

Erland R. Nelson, M.D.
Speakers Bureau and Seminar Committee

Maynard M. Cohen, M.D.
Seminar Subcommittee

Madison H. Thomas, M.D.
Chapter and Service Development Committee

Ellen R. Grass
Joint PAB-Board GLC Committee

David D. Daly, M.D.
Ad Hoc Gas-Liquid Chromatography Accreditation and Standards
Subcommittee
Ad Hoc Gas-Liquid Chromatography Technical Advisory Subcommittee

Adolph L. Sahs, M.D.
Ad Hoc "Consensus" Committee

Local Governing and Advisory Bodies

As we hope we have already made clear similar structures are in existence in every unit of the Epilepsy Foundation of America. Appended to this further statement is a complete list of local Chapter presidents, all of whom would be happy and proud to report upon the activities of their units. Also, more than 575 physicians are active on our local Professional Advisory Boards.

Need for Clarification

The internal workings of the Foundation (which was defined defined in our April 5 statement as essentially a confederation) need further emphasis because the questioning to date seems to reveal certain misunderstandings as to functions. For example, powers have been attributed to staff members which those staff members do not, in fact, possess. Most important of all, there does not appear to be recognition of the very nature of a voluntary health organization, namely: it consists primarily of unpaid citizen-volunteers.

Beyond that, questions in regard to volunteer knowledge and involvement should, obviously, be directed to the proper person. Questions about accounting and finance, for example, should not go to a medical doctor but rather to EFA's Treasurer and Chairman of the Finance Committee, Mr. Thomas A. O'Neill, who is both a lawyer and a certified public accountant. He is a member of the firm of Councilor, Buchanan and Mitchell.

Questions about EFA publications should go to Neal Gillfitt, Chairman of the Board's Public Information and Education Committee and to Dr. Fernando Torres of the University of Minnesota, Chairman of the Publications Committee of the Professional Advisory Board.

The same is true of every other area of expertise; there is a committee which exercises responsibility and control.

I have the feeling it has, perhaps, not been made sufficiently clear that: "Staff proposeth and Board disposeth"; that staff carries out directives of all-volunteer bodies; and that there is constant scrutiny by Board committees -- exercised through monthly reports and in various other ways -- of all operations.

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This is a list of citizen-volunteers who serve as Presidents of EFA Affiliated Chapters and Provisional Chapters. It does not include Information Contacts, although these too can be provided.

ALABAMA

Epilepsy Chapter of Mobile and Gulf Coast, Inc.
Mobile, Alabama

Mr. Homer Sessions,

Alabama Council on Epilepsy, Inc.
Birmingham, Alabama

Mr. William Eddins

North Alabama Chapter
Huntsville, Alabama

Mr. Thomas A. Bryant

ALASKA

Anchorage Area Epilepsy Society
Anchorage, Alaska

Thomas R. Feller, M.D.

ARIZONA

Central Arizona Regional Epilepsy Society
Phoenix, Arizona

Mr. D. Jay Ryan, President

Epilepsy Society of Southern Arizona
Tucson, Arizona

William P. Masland, M.D.

ARKANSAS

Arkansas Epilepsy Society
Little Rock, Arkansas

Mr. Robert T. Douglass

CALIFORNIA

California Epilepsy Society (CES)
Sherman Oaks, California

Charla Reidel

Contra Costa-Alameda Epilepsy League
Richmond, California

Mr. Delmar Kramer

Kern County Epilepsy Society
Bakersfield, California

Mr. Jerry Wear

Los Angeles County Epilepsy Society
Los Angeles, California

Dr. Leon Oettinoer

Orange County Epilepsy Society
Santa Ana, California

Mrs. Betty Smith

Riverside-Imperial Counties Epilepsy Society
Riverside, California

Mr. Eugene D. Hamilton

San Bernardino County Epilepsy Society
San Bernardino, California

Mr. Roy Razo

San Diego County Epilepsy Society
San Diego, California

Mr. Joseph Jessop, Jr.

San Francisco County Epilepsy Society
San Francisco, California

Mr. Salvador P. Guglielmino

Northern Santa Barbara County Epilepsy Society
Santa Maria, California

Mr. Jerri Talaugan

Sacramento Area Epilepsy Society
Sacramento, California

Mrs. Rose Smith

Tulare-Kings Counties Epilepsy Society
Visalia, California

Mr. Charles Cheatham

Ventura County Epilepsy Society
Ventura, California

Mrs. Richard Johansen

Epilepsy Society of Southern Santa
Barbara County
Santa Barbara, California

Mr. Barnard Norris

COLORADO

Colorado Epilepsy Association
Denver, Colorado

Mr. Maynard Hesselbarth

Southern Colorado Epilepsy Association
Pueblo, Colorado

Mr. Albert Madrid

Western Colorado Chapter
Grand Junction, Colorado

Mrs. Herbert Wright

CONNECTICUT

Epilepsy League of Greater Hartford
West Hartford, Connecticut

Mrs. Thelma Dietsch

Southern Connecticut Chapter
Bridgeport, Connecticut

Mrs. June Young

DELAWARE

Delaware Epilepsy Association
Wilmington, Delaware

Mr. Louis Talley

DISTRICT OF COLUMBIA

Washington, D.C. Area Chapter
Washington, D.C.

Mr. Gerald Edelstein

FLORIDA

The Epilepsy Association of Central Florida
Winter Park, Florida

Mr. Harold Drees

Florida Epilepsy Foundation
Tallahassee, Florida

Judge Joe Crowell

Greater Miami Epilepsy Foundation, Inc.
Miami, Florida

Mr. John R. Edwards

Gulf Coast Chapter
Tampa, Florida

Barbara H. McMerney

Jacksonville Chapter
Jacksonville, Florida

Mr. Winston Betha

Palm Beach County Chapter
Delray Beach, Florida

Mr. William F. Cassidy

Sarasota Council on Epilepsy
Sarasota, Florida

E. Weston Littlefield

Florida Epilepsy Foundation of
Escambia County
Pensacola, Florida

Judge Joe Crowell

Pinellas Epilepsy Foundation, Inc.
Seminole, Florida

Mr. Victor W. Worledoe

GEORGIA

Georgia Chapter
Atlanta, Georgia

Mr. John D. Furman, Jr.

BEST COPY AVAILABLEHAWAII

Hawaii Epilepsy Society
Honolulu, Hawaii

Col. Thomas W. Kelly

IDAHO

Idaho Epilepsy League
Boise, Idaho

Karen A. McAlister

ILLINOIS

EFA Chicago Metropolitan Chapter
Chicago, Illinois

Sy Nordick

Rock River Valley Epilepsy Association
Rockford, Illinois

Mr. Ed Lanoley

INDIANA

Tri-State Epilepsy Association, Inc.
Evansville, Indiana

Mr. Charles W. Kroener

IOWA

Iowa Chapter Epilepsy Foundation of America
Des Moines, Iowa

Dr. Moorcraft

Aligned Community of Epileptics
Waterloo, Iowa

Mrs. Mary Martin

Epilepsy Society of Area XI
Des Moines, Iowa

Dr. William Teppert

Siouxland Area-Iowa Chapter
Sioux City, Iowa

Mrs. Patricia Smith

Epilepsy Society of Area X
Cedar Rapids, Iowa

Mr. Bill Bickett

KANSAS

Epilepsy Foundation of America, Kansas Chapter
Wichita, Kansas

Mr. Hal Malone

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KENTUCKYEpilepsia of Louisville
Louisville, Kentucky

Mrs. Virginia Farmer

Jackson Purchase Chapter
Paducah, Kentucky

Mr. Dan Williamson

LOUISIANASouthwest Louisiana Chapter
Lake Charles, Louisiana

Rose C. Wilson

Louisiana Epilepsy Association
New Orleans, Louisiana

Mr. Reginald T. Badeaux

MAINEEpilepsy, Inc.
Maine Chapter
Boston, MassachusettsMARYLANDChesapeake Association for Epilepsy
Baltimore, Maryland

Mr. William J. Lowman

MASSACHUSETTSGreater Springfield Epilepsy Association
Springfield, Massachusetts

Mr. Peter Picknally, Jr.

Epilepsy Society of Massachusetts, Inc.
Boston, Massachusetts

Mr. John R. Auchter

MINNESOTAMinnesota Epilepsy League
St. Paul, Minnesota

Mrs. Sophie Reuben

Central Minnesota Epilepsy Society, Inc.
St. Cloud, Minnesota

Mrs. Beverly Graf

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West Central Seizure League
Willmar, Minnesota

Mrs. Lucille Sebring

MISSISSIPPI

Mississippi Council on Epilepsy
Jackson, Mississippi

Mr. Archie B. Lancaster, III

MISSOURI

Greater Kansas City Epilepsy League
Kansas City, Missouri

Mr. M. R. Knickerbocker

Missouri Epilepsy Federation, Inc.
St. Louis, Missouri

MONTANA

Big Sky Epilepsy Association
Billings, Montana

Charlotte Cullum

The Copper Chapter of Great Falls
Great Falls, Montana

Mary E. Miller

NEBRASKA

Nebraska Epilepsy League
Omaha, Nebraska

Mr. William B. Woodruff

NEVADA

Southern Nevada Epilepsy Society
Las Vegas, Nevada

Mr. Barry Klick

Northern Nevada Epilepsy League
Reno, Nevada

Vonita Stephens

NEW JERSEY

New Jersey State Chapter
New Brunswick, New Jersey

Mr. Arthur Green

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NEW MEXICO

Epilepsy Foundation of New Mexico
Albuquerque, New Mexico

Mr. Arrowsmith

NEW YORK

Epilepsy Association of Western New York, Inc.
Buffalo, New York

Mr. Joseph M. Byron

Epilepsy League of Tri-Cities
Albany, New York

Edward C. Diamond, Ph.D.

Greater New York City Chapter
New York, New York

Alfred M. Watson, Ph.D.

Oneida County Chapter
Utica, New York

Mr. Arthur E. Lawrence, III

New York State Organization
Albany, New York

Edward C. Diamond, Ph.D.

Epilepsy Foundation of Hudson Valley, Inc.
Poughkeepsie, New York

Mr. Joseph F. Frisco

Nassau County Chapter, Inc.
Hempstead, New York

Mr. Fred Abrams

Epilepsy Association of Suffolk
Greenlawn, New York

Mrs. Jane McGarity

NORTH CAROLINA

Epilepsy Association of North Carolina
Charlotte, North Carolina

Mr. A. J. Morton

OHIO

Epilepsy Association of Ohio
Canal Winchester, Ohio

Mrs. Margaret Sprigg

Greater Cincinnati Council for Epilepsy, Inc.
Cincinnati, Ohio

Mrs. Florence Fogle

Epilepsy Association of Franklin County
Columbus, Ohio

Mr. Francis Silver

Greater Cleveland Chapter
Cleveland, Ohio

Miss Dorothy Poitlucci

Mahoning Valley Chapter
Youngstown, Ohio

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OREGONEpilepsy League of Metropolitan Portland
Portland, Oregon

Mr. Robert Scrivner

Epilepsy League of Lane County
Eugene, Oregon

Barbara Lieuallen

PENNSYLVANIAAllegheny Plateau Chapter
Pittsburgh, Pennsylvania

Mr. Ernest Pearl

Epilepsy Society of Lycoming County
Williamsport, Pennsylvania

Mr. George E. Orwig, II

Philadelphia Chapter
Philadelphia, Pennsylvania

Mr. John A. Keeley

SOUTH CAROLINAPiedmont Epilepsy Association
Easley, South Carolina

Mr. Paul Lonsdale

TENNESSEEMemphis Epilepsy Society
Memphis, Tennessee

Mr. Gene Thomas

Bi-State Chapter
Clarksville, TennesseeTEXASDallas Epilepsy Association
Dallas, Texas

Dr. Carmen Michael

High Plains Epilepsy Association
Amarillo, Texas

Rev. Lael M. Smith

Houston Epilepsy Association
Houston, Texas

Mr. Perry Clark

San Antonio Epilepsy Association
San Antonio, Texas

Morris H. Lampert, M.D.

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UTAH

Utah Epilepsy Associaton
Salt Lake City, Utah

Ger. Ray D. Free, USA (Ret.)

VERMONT

Vermont Epilepsy Association, Inc.
Burlington, Vermont

Mr. David Curtis

VIRGINIA

Greater Tidewater Epilepsy Associaton, Inc.
Chesapeake, Virginia

Mrs. Leon Brooks

WASHINGTON

Eastern Washington Epilepsy Society
Spokane, Washington

Mr. Orville Thomson

Western Washington Epilepsy Society
Seattle, Washington

Mr. Ben Reppond

WEST VIRGINIA

Mountain State Epilepsy League
Huntington, West Virginia

Pauline Harvey, Ph.D.

Central West Virginia Epilepsy League
Clarksburg, West Virginia

Miss Wilma Jean Pertz

WISCONSIN

Wisconsin Epilepsy Association
Madison, Wisconsin

Mr. Horace K. Tenney, III

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INFORMATION CONTACTS

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Big Bend County Epilepsy Foundation
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Richard Matheson
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Heart of Illinois Epilepsy League
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President, C-WEEDS
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Mrs. Jack Holycord, Secy.
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Columbus, Indiana 47201

Mrs. Bonny Williams
Dept. of Mental Health
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Frankfort, Kentucky 40601

Epilepsy Society of Greater Boston
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Mid-Missouri Epilepsy League
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Miss Ann Barton
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Lincoln, Nebraska 68502

Mrs. Clinton Bereuter, Chairman
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Bloomfield, Nebraska 68718

Ms. Madelin Towers
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Vestal, New York 13650

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Mr. Harvey Millman
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Santa Clara County Epilepsy Society
San Jose, Calif.

Fresno County Epilepsy Society
Fresno, Calif.

Sonoma County Epilepsy Society
Santa Rosa, Calif.

Savannah Sub Chapter of the Georgia Chapter
Savannah, Georgia

Epilepsy League of Leavenworth County
Leavenworth, Kan.

Central Kentucky Epilepsy Foundation
Lexington, Ky.

Lafayette Epilepsy Chapter
Lafayette, La.

Seacost Epilepsy Association
Kittery, Maine

Epilepsy Center of Michigan
Detroit, Michigan

Arrowhead Epilepsy League
Duluth, Minn.

Butte Epilepsy Association
Butte, Montana

New Hampshire Chapter, EFA
Manchester, N.H.

Epilepsy Society of Onondaga County
Syracuse, New York

Epilepsy League of Oregon
Portland, Ore.

Permian Basin Chapter
Midland, Texas

Ms. Nancy doen
Wichita Falls, Tex.

El Paso Epilepsy Association
El Paso, Tex.

Wisconsin Epilepsy League
Milwaukee, Wisc.

Wyoming Epilepsy Association
Cheyenne, Wyo.

3. INCIDENCE, PREVALENCE AND OTHER SIGNIFICANT
DATA ON PROFESSIONAL QUESTIONS

I would like to comment in some detail on the testimony of Dr. Donald Harting, who was for some months Director of the National Institute of Child Health and Human Development, and Dr. John F. Kurtzke, a professor of Neurology at Georgetown University (I do not know Dr. Kurtzke, but I do know the Head of the Department of Neurology at Georgetown, Dr. Desmond S. O'Doherty, who is a member of our national Professional Advisory Board).

Most EFA people at every level -- on the national Board of Directors, on the national Professional Advisory Board, on headquarters staff, in local chapters and on local chapter Professional Advisory Boards -- are today well familiar with the terms "incidence" and "prevalence" and the NINDS Monograph #14 "The Epidemiology of Epilepsy: A Workshop" which reports on a November 4-5, 1971 seminar. Indeed, seven members of our national Professional Advisory Board (Drs. A. B. Baker, David D. Daly, Warren V. Huber, Jerome K. Merlis, J. Preston Robb, Fernando Torres and A. Earl Walker) attended that Workshop along with a staff observer, Thomas M. Ennis. Other participants included Dr. Patrick F. Bray, active with our chapter in Salt Lake City, Dr. Robert J. Gumnit, head of the Professional Advisory Board in Minneapolis-St. Paul, and Dr. Richard L. Masland, who is on the Professional Advisory Board in New York City.

The monograph is a valuable contribution to knowledge but is by no means definitive and I very much doubt that many of the participants in that Workshop would so view it. If I may telescope the conclusion, after 167 pages, it would be: this is a very complex subject warranting careful further study.

Considerable further additional information is of course already available and needs to be evaluated. I will cite several such references including the following:

- A. The 1971 Epilepsy trauma study by Dr. William Caveness, Chief of Laboratory of Experimental Neurology at the National Institute of Neurological Diseases and Stroke, was reported on at the 22nd Western Institute on Epilepsy co-sponsored by the Epilepsy Foundation of America. The findings follow:

"It is conservatively estimated that there are 400,000 injuries each year that will result in one or more posttraumatic attacks. Of these, 200,000 will provide a therapeutic problem in the control of seizures."

Drs. Rapport and Penry reported in "Pharmacologic Prophylaxis of Posttraumatic Epilepsy," *Epilepsia*, 1972, that 100,000 new cases of epilepsy a year due to head injury alone is the most conservative estimate. This is "incidence" and if these projections, based on head injury alone, are correct, then Dr. Kurtzke's statement that "each year there are some 80,000 new cases in the U.S. population of 200,000,000" requires much further discussion.

- B. Rose, S. W., Penry, J. K., Markush, R. E., Radloff, L. A., and Putnam, P. L., "Prevalence of Epilepsy in Children," Epilepsia, February, 1973. A survey questionnaire was sent to all parents of 3rd grade children in Washington County, Maryland, resulting in 18.6 per 1,000 prevalence rate.
- C. The NINDS Profile entitled "Research Profiles - 1973" which was prepared as background information for 1973 Congressional Hearings. The epilepsies are covered on pages 18-30. This brochure has the following to say:

"The epilepsies are estimated to afflict between two and four million persons in the United States. Many responsible medical groups suspect that the prevalence is much higher. It is difficult to determine the number because victims hide their disorders to avoid adverse effects to their lives which arise from public fear and ignorance."

- D. In their publications, National Association for Retarded Citizens estimates 1 in 4 retarded has seizures (epilepsy). They estimate their patient population at 6 million.

Approximately one-third of cerebral palsied children have seizures (estimated population, 750,000).

An English study estimated approximately 20% of the total population with epilepsy was identifiably mentally retarded.

Leaving out the Cerebral Palsy figure entirely, and including the Mental Retardation estimate to 1 in 6 with seizures (1,000,000) then conservative extrapolation comes to more than the four million figure, taking the epilepsy population as a whole.

Countless epidemiological studies have been conducted in various geographical locations and under varying conditions for many years but the data is inconclusive because of the lack of consistent survey conditions. Gross inadequacies are pointed out in each study. The definition of the condition can range from "at least one seizure" where the resulting number of epileptics was determined to be 14% of the population in a village in Guam where each person was known to the surveyor and no stigma is attached to the disorder (Kurland), through exclusion of febrile convulsions, to specific medical classifications of recurrent epileptic seizures which have required physicians' assistance as in Krohn's survey of epilepsy in northern Norway which revealed 2.3 per thousand population.

The Kurland Rochester study is limited by the fact that it only dealt with a small urban population and only the reports of physicians and hospitals were included. His findings were 3.65 per thousand. Most studies have depended on the medical community to furnish the data although some have surveyed the school and its staff for determinations of the number of epileptic school

children. This has not proved satisfactory either since the result in one study was half of the number previously found through physicians' reports.

It is apparent that an ideal epidemiological survey has not been conducted that has determined an accurate number of epileptics in any general population area. The need for a methodology to be developed is great, but in the meantime, it is imperative that we work with the figures that are available to us, all the above being low projections of the enormity of the problem. This is due to the size of the sampling, the method by which the data was gathered, the refusal to admit epilepsy, the lack of a proper definition for "epilepsy," etc. In light of this, the Epilepsy Foundation of America's Professional Advisory Board some time ago issued the following statement:

The Professional Advisory Board of the Epilepsy Foundation of America estimates that at least two percent of the present population of the United States, or a minimum of four million persons, suffer from some form of convulsive disorder. Previous estimates, based primarily on World War I and World War II Selective Service rejection figures, took into account only a limited group of young, adult males. Further, these estimates did not include persons who were in fact suffering from a convulsive disorder, but were rejected for any of a number of other reasons.

In addition, because of the stigma which surrounds epilepsy and other convulsive disorders, many persons with such disorders conceal their illness, often relying on mail order treatments or receiving no treatment at all.

Moreover, discriminatory laws in many states, as well as employment practices and insurance underwriting policies aimed at excluding the epileptic, give the patient and members of his family a strong incentive to conceal the disorder. This, coupled with the fact that epilepsy is not contagious, and therefore not a "reportable" disease, has cast additional serious doubt on the previous estimates.

For these reasons, the official estimate of Epilepsy Foundation of America of the total number of persons suffering from convulsive disorders in the United States is now established as two percent, which, on the basis of the present population, is approximately four million persons.

We have other clues to the number of persons with epilepsy, though they are not compiled in the manner of epidemiologists. For example, a recent issue of *Mental Retardation News* (February, 1974) reprints an article which originally appeared in the *Wisconsin Association for Retarded Citizens News*. It stated that one out of four mentally retarded children has seizures (epilepsy). The estimated number of mentally retarded in this country is around 6 million which would mean that 1.5 million are epileptic and retarded. A British study (Abernathy, R. S. J. *Lancet*. 86:115, 1966) found about 20 percent of the people who have epilepsy to be mentally retarded. If the estimated 1.5 million who are mentally retarded and epileptic represent only 20 percent of the total epileptic population, then the size of that total population is clearly consistent with the Professional Advisory Board's estimate.

Subcommittee Experts Versus Other Experts?

On professional subjects, in any field, there will always be a wide variety of opinions put forth by well qualified, well intentioned people. But it is highly unlikely that many will possess professional credentials superior to those possessed by members of EFA's national Professional Advisory Board, particularly:

A. B. Baker, M.D., Ph.D., Regents' Professor and Head of the Department of Neurology at the University of Minnesota Medical School, founder and past president and current Chairman of the Board of Epilepsy Foundation of America, editor of the foremost text in the field, Clinical Neurology, now in its third edition. He served for 15 years as Chairman of the National Committee for Research in Neurological Disorders and was also President of the American Neurological Association.

David D. Daly, M.D., Ph.D., Professor of Neurology at the University of Texas, Southwestern Medical School in Dallas, Chairman-Elect of the Professional Advisory Board of the Epilepsy Foundation of America, President of the International League Against Epilepsy, scientific consultant to NINDS, former member of the HEW Secretary's National Advisory Committee on the Epilepsies. He holds an M.D. and a Ph.D. from the University of Minnesota.

Adolph Sahs, M.D., Professor and Head (for the past 26 years) of the Department of Neurology at the University of Iowa College of Medicine, past president of the American Academy of Neurology, co-author of the classical text, Neurology, now in its 6th edition, and author of over 60 publications. Dr. Sahs is chairman of EFA's Professional Advisory Board.

Certainly there can be no confusion as to where governmental expertise on the epilepsies resides; that is the National Institute of Neurological Diseases and Stroke. There are many fine scientists there including Dr. Donald B. Tower and Dr. James J. Cereghino. But the government's chief epileptologist and a man with a world-wide reputation is Dr. Kiffin Penry, the Secretary-General of the International League Against Epilepsy and the president-elect of the American Epilepsy Society. It is surprising that his counsel was not sought in attempting to define incidence and prevalence.

EFA Leadership

I would go further because I believe that it illustrates the vitality and thoroughness of EFA. At my personal instigation, in 1972, EFA compiled and published a document entitled "Spectrum - A compendium of Current Opinion and Fact on Several Key Questions About Epilepsy" setting forth a range -- but by no means the full range -- of professional opinion on various key questions. For many of us thought it important that the professional community make a beginning on the difficult task of resolving -- to at least some extent -- these differences of opinion.

The national Professional Advisory Board pondered these matters for many months.

The assignment of resolving them was given to Drs. Baker, Sahs and Daly, who worked long and hard on the project. I know because I worked along with them. The result is a document entitled "Consensus - A Compendium of What is Believed to be the Majority Professional View on Several Key Questions about Epilepsy" and I introduced it into the record of these proceedings the morning of April 9. Had it been consulted -- or had I been given an opportunity to refer to it -- I believe that we would all have a clearer picture of just what we are talking about. I urge that it be reviewed in detail by the Subcommittee and by the entire Labor and Public Welfare Committee.

4. EFA LITERATURE AND STUDIES

Dr. Harting made references to five publications of the Foundation and I would like to comment on each in the same order as he did.

Four-page pamphlet entitled "Epilepsy is America's Concern." This pamphlet was developed by EFA staff in 1969. Dr. Harting is correct that a table meant to illustrate "prevalence" is incorrectly labeled "incidence." (If you will note "Data Pak" corrected this miswording by its chart indicating "no. affected" (cancer, heart, tuberculosis and respiratory diseases and cerebral palsy).) In our newest publication, "Facts and Figures," a chart of the "estimated cases" of neurological diseases is included. There are other minor deficiencies in the "Epilepsy is America's Concern" text and no additional copies have been ordered for a considerable period of time, and no future distribution is planned by the Foundation.

It is very difficult to find writers who can write on a complex subject in a fashion understandable to the general public and who also have the technical knowledge and/or scholarship required to illuminate technical and complex subjects. EFA has long searched for such people and has tried many in this role.

- A. The Senator asked about the figure of 25% of controlled epileptics being unemployed and how this figure was determined. Let me refer you to a study by R. D. Dennerll, et al., published in *Epilepsia*, volume 7, 1966, pps. 318-329, entitled "Neurological and Psychological Factors Related to Employability of Persons with Epilepsy," in which is stated:

Although employment is repeatedly cited as one of the major problems confronting persons with epilepsy, surveys over the past 20 years have consistently shown rates of employment ranging from 74-90% (5, 12, 13, 16). Consequently, despite the existence of adverse attitudes, the majority of adults with epilepsy appear to be able to obtain and hold employment, and have been shown to be employed in all types of occupations (19, 20).

If 75-85% of persons with epilepsy can have their seizures controlled sufficiently to live a normal life, then it seems reasonable to assume that these persons might be the same ones shown by numerous surveys to be employed. The remaining 15-25%, therefore, should represent the epilepsy group with an employment problem.

A number of studies or surveys of this problem have reported findings suggesting one or more factors other than seizures related to employment problems.

- B. In a survey conducted by EFA, 42.1 percent reported problems in getting a job, 33.8 percent reported problems holding a job, and 46.3 percent reported being turned down for a job because of epilepsy. Twenty nine percent had been dismissed from jobs because of seizures. Problems with employment dominated the sections of the survey in which people with epilepsy were asked to identify their needs.

Most survey results have been processed by the American University Department of Computer Services. The computer program utilized has been SSP (Statistical Packages for Social Scientists).

"Data Pak" - Dr. Harting states that this single sheet states that "the primary purpose of the Epilepsy Foundation of America is research." Nowhere in the piece do I find anything leading to that conclusion. On the contrary, the piece cites nine purposes of EFA, also found on page 1-3 of the original Statement. Dr. Harting faults this piece because it makes no mention of the National Epilepsy League. If this is a fault it is a fault shared by others and reference is made to the history of the epilepsy movement and accompanying chart (see pages 3-3, 4-3 of the original Statement).

Data Pak is exactly what its name implies - "a single sheet packed with data" - and there are a great number of other things that might have been included had space not been limited. It was created in 1968 and since it was revised in 1971 we have distributed 300,000 copies and the sheet has been widely praised. It is, however, no longer offered and has been replaced by a pamphlet entitled "Facts and Figures on the Epilepsies." In the past year, our entire literature system has been revamped to reflect the most accurate professional work published, and we have documented much of the factual content with footnotes and references in addition to the fact that no information is presented without backup materials available.

"Cost of the Epilepsies" - I have personally talked with hundreds of persons with epilepsy and parents of children with epilepsy and the figure "\$100" is the most frequently mentioned to me when drugs are discussed. I make no figure "\$100" is the most frequently mentioned to me. I make no claims as to its scientific accuracy. But it does not differ with the \$500 that Dr. Harting mentions appeared on page 43 of the "Cost" report. He states that the "Cost" reports "the average yearly cost of drugs for an epileptic is \$500." Actually, page 42 states "The National Institute of Neurological Diseases and Stroke has calculated the yearly cost of Dilantin, prescribed in combination with barbiturates, to be approximately \$500.00 per patient. This estimate includes the physician fees necessary for bi-annual reexamination and monitoring."

Broad outlines of this study were originally formulated by Ms. Melba A. Gandy based on her knowledge of government which extended to the White House (she was with the Office of Emergency Planning) and intimate knowledge of state government derived from many years as Secretary to the Honorable Ferris Bryant, Governor of Florida, gave her an overview of where data was most likely to be found. The actual collection of the data (which are basically from governmental documents) and writing were done by a person with a master's degree in Sociology.

It should be noted that at its first printing the report was sent to various persons in government for their information, comments and recommendations. The "Cost" study has been praised by many including key government officials in the health fields, members of Congress and state health officials. Below are some quotes.

Robert S. Stone, M.D., Director of NIH. "The Foundation's report on 'The Cost of the Epilepsies' is indeed, a most interesting and valuable document. I do understand how difficult it is to make these projections and how impossible it is to verify some of these figures. In spite of these obstacles, however, you have approached the many aspects of the subject in a most thoughtful and orderly manner and have developed a body of knowledge long needed in assessing the magnitude of the problem."

Caspar Weinberger, Secretary, HEW. "will be a helpful addition to the existing statistics on the cost of this illness to Americans"

Bertram Brown, M.D., Director, National Institute of Mental Health (HEW). "useful step in planning a national strategy and in clarifying for the American people the magnitude of the problem in economic terms."

Senator Jacob Javits (R-N.Y.). "will be a most helpful reference to the committee in its consideration of developmental disabilities legislation and will provide important data on the cost benefit ratio of Federal support."

Harry Weaver, Executive Director, National Advisory Committee on Multiple Sclerosis. "a very revealing and convincing document on a subject about which far too little factual information is available. In view of the inadequate data available, you have provided a most worthwhile service."

Senator Edward Kennedy (D-Mass.). "very comprehensive and worthwhile document"

J. M. Stubblebine, M.D., Director of Health, State of California. "most comprehensive inventory of the economical costs of epilepsy that has come to my attention"

Honorable Margaret Heckler (R-Mass.). "It is so important that we do ascertain these figures so that a responsive and effective program can be developed to confront the challenge of epilepsy."

Actual research was conducted at the Library of Congress, the National Library of Medicine, the offices of the various agencies mentioned in the report as spending money on epilepsy and in EFA's Information Center and Library. The study was read by several economists. A quote from the Introduction to the Cost Study, I believe, states the intent rather clearly as follows:

the most outstanding difficulty presented as a deterrent to an accurate cost estimation is the notorious absence of statistical data concerning persons with epilepsy. . . . this report is not intended to be a comprehensive and statistically accurate estimation of the total cost of the disorder. It is merely an attempt to provide some understanding of the scope of the economic implications, where no more than educated guesses have existed in the past.

The rest of the Introduction clearly illustrates our stance as well as our frustration in attempting to learn more about this very elusive statistical problem. It is for these -- and many, many other -- reasons that a National Commission and a National Plan are needed.

Fund Raising Letter. All guidelines, policies and application reviews for research grants originate with EFA's Professional Advisory Board. Research grant applications are accepted until April 15 of the year preceding that in which the study will take place. Applications are then referred to the committee members for preliminary review with a final meeting for competitive evaluation of all projects. Awards are announced in November for funding which will commence during the following year.

National Spokesman. Dr. Harting next attacks an item in one issue of our newspaper, the headline of which implies partial support by the use of the word "aids." There are of course space limitations in a newspaper as every journalist will testify. However, perhaps the best judge of how EFA reports is Dr. Reginald Bickford himself. Dr. Bickford, when contacted by telephone on April 16, 1974, said that EFA funds had played a critical role in the development of the home telephonic epilepsy monitoring technique developed in his laboratory. Indicating the importance of EFA funding to the project he said:

"The further development of the technique has not moved much further because EFA was unable to fund our most recent grant application to continue this research."

It should also be noted, from the attached documents, that four of the six authors of a professional article detailing the technique of telephone EEG monitoring were supported by EFA awards.

EFA publications are reviewed by a variety of people, primarily the Publications Committee of the Professional Advisory Board headed by Dr. Fernando Torres of the University of Minnesota. But other people and authorities review material depending upon its content. Sometimes these are other members of the national Professional Advisory Board; sometimes they are outside authorities, experts in the particular area, government officials, etc.

This careful, painstaking review is found burdensome by some, but it is absolutely essential to an organization of our kind. Since 1971 all material goes through an approval process as indicated on the last page in this section.

Frequently the first run is in a small quantity so that comments and recommendations can be considered and changes made if found to be necessary before quantity runs are made. Despite our best effort, there is always the possibility of human error, but every normal precaution is taken to eliminate it.

This is the knowledge that we are aware of. If further study is needed we urge once again the creation of a National Commission to develop a National Plan. The recommendations of such a body under governmental auspices would not only help to clarify many of the areas discussed in the hearings, but also and more importantly serve the persons with epilepsy who need the services.

We are unacquainted with the incident related by Dr. Harting in regard to the compilation of figures at NINDS but knowing that Institute we would very much question this recital.

Purpose of a National Plan is to determine whether by spending dollars in certain ways we can in time reduce expenditures in other areas.

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5. EFA'S GREATER NEW YORK CHAPTER

Mr. Frank Self's testimony illuminated the operation of a very fine local chapter. Although not yet large enough to take care of all the persons with epilepsy who need help, the organization which has had the benefit of first-hand help and assistance from Associate Executive Director Don L. Organ (who moved it into its present quarters), provides fine and professional services.

Mr. Alfred N. Watson, LL.B., Ph.D., who is the President of the Greater New York Chapter, is also a member of the national Board of Directors and has full and complete information on all EFA operations. He typifies the enlightened citizen volunteer working to improve our society.

Considerable help and assistance has been provided the New York Chapter including financial help. Headquarters records show the following investments over the last six years:

1968	\$ 17,000
1969	21,000
1970	30,000
1971	44,910
1972	23,650
1973	<u>10,000</u>

\$146,560

In addition, in 1973 the Foundation committed itself to loaning the chapter \$2,000 per month interest free payable two years from the date of each loan.

Fund raising in New York City remains a problem but progress is being made. The cost ratio is relatively low principally because it is measured against a total income of \$182,706 of which \$95,733 was from governmental grants. The Foundation also assisted the chapter in developing its donor list. In 1968 it turned over to the chapter one of its very best and most productive lists and has done selected mailings in 1972 and 1973 in an effort to enlarge those lists.

We anticipate that the chapter will continue to make worthwhile progress.

6. REGULATORY AGENCIES IN THE STATES OF
PENNSYLVANIA AND NORTH CAROLINA

EFA has already reported on the situation in the Commonwealth of Pennsylvania. We have three chapters in that state (Lycoming County, Pittsburgh and Philadelphia) although there is presently a need for more. A state organization is now in the process of formation with leadership provided by Mr. George E. Orwig, II, a long-time member of our National Board of Directors. He is President of the Lycoming County Chapter which has a very active program especially during Epilepsy Month in November. This chapter also provided Dilantin and Phenobarbital at reduced cost to persons with epilepsy. For a fine description of the activities of the Philadelphia Chapter headed by Dr. Richard N. Harner see February 3, 1974 issue of the PHILADELPHIA INQUIRER.

On April 9, 1974, TV station WCAU in Philadelphia carried an interview with Carol Cochran which EFA believes misstated the situation there. On April 19, 1974, Thomas M. Ennis presented a rebuttal over the same television station.

EFA regards Ed J. Edgerton, Special Assistant for Licensing - Charitable Solicitations, North Carolina Department of Human Resources, as a friendly critic, well aware of the need for an epilepsy organization in the state of North Carolina. We anticipate no undue difficulties in resolving the situation there.

The EFA Executive Committee has suggested -- and we have discussed with Mr. A. J. Morton, Jr., President of the Epilepsy Association of North Carolina, a test program the main elements of which include the following:

- (1) The mailing would be under the name of a joint committee representing both EFA and North Carolina Epilepsy Association.
- (2) The entire package would be prepared and addressed in Washington and could either be mailed from there or shipped in bulk to a mailing address in North Carolina. Returns would be addressed to a North Carolina address, where they would be received and banked in the name of the joint committee.
- (3) Net receipts, after payment of all campaign expense, would be divided fifty percent for local chapter development and community service in North Carolina, fifty percent to EFA to assist in public education, research, government liaison and other programs.
- (4) The solicitation letter, and any accompanying literature would contain the names of the EFA Board and the North Carolina Board and endorsements by prominent North Carolina citizens, and would describe ongoing projects, both local and national.

7. PROBLEMS INVOLVED IN REDUCING FUND RAISING COST RATIOS
BY DIVERSIFYING ACTIVITIES AND TRANSFERRING
FUND RAISING TO THE LOCAL LEVEL

EFA Board Expresses Concern about Undue Reliance upon Direct Mail

The EFA Board of Directors has for some time been concerned that EFA has, of necessity, unduly relied upon Direct Mail as its main source of income. Realizing the need to develop strong local chapters with independent Fund Raising programs, EFA late in 1973 began to focus increased headquarters staff attention on local funding. In addition to specific Fund Raising materials, EFA has assigned certain headquarters staff and regional field staff to stimulating specific local chapter fund raising.

Increased Emphasis upon Chapter Fund Raising May Well Increase the Cost Ratios

As more emphasis is placed on developing local chapter funding, there will be a sizeable cost increase. Each staff person assigned to fund raising will thus increase the cost ratio . . . It has been estimated that a staff person in a fund raising position now would annually have to raise at least 4 or 5 times his salary and expenses in order to offset this escalating cost.

The Foundation is continually faced with a contradiction -- increasing fund raising emphasis will greatly increase cost. Therefore, the Foundation must strike a delicate balance so as not to negate the effects of developing local funding techniques. It appears the Foundation is moving as rapidly as is possible in developing local chapter fund raising.

Eventual Admission into Federal Giving Campaign

As EFA's combined cost ratio (Headquarters and Affiliates) decreases to 25% or less, hopefully EFA will be admitted to membership in the Federal Government's Combined Fund Raising Campaign. This alone will enable EFA and its many local organizations to further reduce cost ratios. However, again we are faced with the paradox that as long as the cost ratio (combined) exceeds 25% EFA will apparently be denied admission to the Federal Campaign.

EFA Prepares Material for Chapter Use Concerning United Fund Participation

The EFA Board of Directors has always followed an optional policy of allowing local units (affiliates) to join United Funds. In many instances a smaller FFA chapter can readily benefit from United Fund Participation.

The Possible Management of EFA's Direct Mail Program by Local EFA Affiliates

For some time EFA's Board of Directors has examined the possibility of having EFA's chapters on a State or Regional basis be responsible for EFA's present national direct mail program. In fact, EFA has developed more than 20 programs where mailings were done by local chapters. The results thus far have not been encouraging, since with rare exceptions, little or no fund raising expertise exists at the local level.

Consideration of Risks in Transferring Direct Mail to State Organizations

in anticipation of more manageable local programs, EFA has encouraged the growth of several state organizations; e.g., Oregon, California, Florida; and is in the process of establishing others. Generally EFA chapters have been patient oriented, not fund raising oriented.

If the National EFA headquarters were to immediately transfer the operation of the direct mail and other national fund raising projects to the local chapters or state organizations, it appears that the results would be negative. As mentioned, the lack of fund raising experience on the local level would preclude success. Thus, as Jack Grimes of the National Health Council stated in his testimony, any transfer of funding functions must be done in such a manner so as not to jeopardize the entire epilepsy movement.

EFA Fund Raising Cost Ratio in Recent Years

Refer to page 1-7 of the Statement for an examination of EFA Fund Raising Cost Ratios. It appears that the figure for 1974 combined (and at this point unaudited) will be approximately 29.5%.

EFA Chapters Show Increase in Local Chapter Revenue

As indicated in the following chart there has been a steady growth of total chapter income during the last three years. It is anticipated that with increased guidance from EFA national this increase will continue.

CHAPTER INCOME*

	1971	1972	1973
Funds from All Sources			
Other than Gov't. Grants	\$ 630,355	\$ 648,431	\$ 780,000
Government Grants	20,443	272,399	520,000
Total Chapter Income	\$ 650,798	\$ 920,830	\$1,300,000

*Figures do not include Michigan

Flow Through to Headquarters

As indicated by the chart below, flow through to headquarters is increasing albeit slowly:

1969	\$ 5,300
1970	\$ 4,000
1971	\$10,300
1972	\$23,200
1973	\$42,147 (incomplete returns)

EFA is Making Increased Progress in Obtaining Non-Mail Sources of Funds

Refer to page 7-7 of the Statement which shows the following revenue for 1973 (subject to final audit).

1973 INCOME BY REVENUE SOURCE (000)

Revenues*	General Fund Budget	General Fund	Restricted Funds	Total
Direct Mail	\$ 3,090	\$ 3,269.2		\$ 3,269.2
Foundations		45.5		45.5
Major Donors	220	44.4	\$ 121	165.4
C & I		20.7		20.7
Wills & Bequests	105	100.4		100.4
Affiliates	87	27.1		27.1
Miscellaneous	45	10.7		10.7
Total Revenues	<u>\$ 3,547</u>	<u>\$ 3,518.0</u>	<u>\$ 121</u>	<u>\$ 3,639.0</u>
Less Affiliates	<u>\$ 87</u>			
	<u>\$ 3,460</u>			

*Subject to Final Audit

As reported by Mr. Gene Pulliam, Chairman of EFA's Fund Raising Committee, to the EFA Executive Committee on April 5, 1974 (again subject to final audit):

"The income received from non-mail sources, exclusive of dues from affiliates (Restricted and Non-Restricted), rose some 20% to \$340,000, which is in keeping with the non-mail funds anticipated for 1973, as outlined in the Fund Raising Committee Report to the Executive Committee dated October 18, 1973."

As Mr. Self of the Greater New York Chapter reported in his testimony given to the Subcommittee on Children and Youth on April 9, 1974:

"I recognize that the National EFA has to have money. At the present time their only major source of income is by mail.

"In ideal terms, it would be much simpler to raise money in New York if National EFA did not raise money simultaneously. It would also be less confusing to the public.

"But we are up against a problem of not having any alternatives. I support a national concept, and I would hate to see the national Epilepsy Foundation of America be cut off from its present source of income, although it frankly does create a problem in New York, because we have duplicate mailings which go to people and just confuse the public."

Thus one of EFA's main chapters fully realizes the need for continuing direct mail until other sources of funding are developed.

Mr. Edgerton, Chief, Solicitation Licensing Section, Department of Human Resources, Raleigh, North Carolina, recognizes the fact that the EFA chapters are not yet able to function as the main source of EFA's national income:

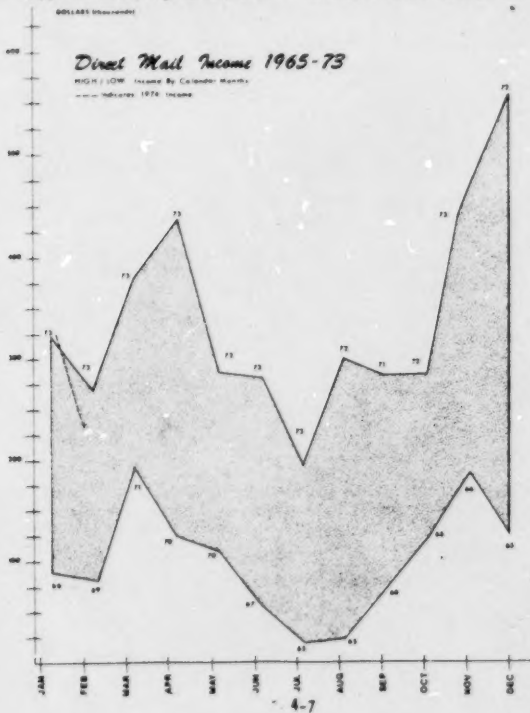
"One: Chapters are not able to assume as yet their role as the main source of National's income.

Thus a modest, but measurable, effort has been made toward becoming less dependent upon direct mail as a source of income. All available options are being explored -- options which would reduce the national headquarter fund raising cost ratio, and at the same time develop strong local (chapter) fund raising sources.

As reported in the Statement, page 1-7, historically the various epilepsy organizations (prior to merger) encountered continuing difficulty in establishing fund raising programs. It now appears, based upon actual results, that EFA has now entered on the first step of this delicate transition of changing the funding pattern of the epilepsy movement.

EFA is also Making some Progress in Leveling out Income "Peaks and Valleys"

At the present time, the peak period -- the time when donors respond in greater numbers and with greater generosity than at any other times during the year -- is December. This undue reliance upon November's Epilepsy Month, Christmas Season generosity, and early-in-the-year returns has made it difficult to plan "cash flow" on a year-round basis so as to have funds when needed for supplies and program services. The chart shows details.



B. SOME COMMENTS BY EFA DONORS

I believe I know the concerns of donors for over the years I have contributed to many organizations, including EFA. In 1972, for example, my personal contributions to EFA totaled at least \$1,307.

Virtually all of our staff also contribute.

Donors already have the means available to a considerable extent to control the use made of their gifts by designating them as restricted to a specific purpose. In my own instance, for example, \$1,000 of my contribution went to start the EFA Research and Training Institute training courses.

I would again call the Subcommittee's attention to the fact that contributions to this Institute (see page 5-6 of the original statement) are used totally for the purpose with no deductions for any administrative costs.

But let me go further. Any organization has its supporters, and it would be surprising if that were not true of EFA. But I personally read many of the letters we received from contributors, and I sincerely believe these samples to be representative.

Typical Donors Comments

"Thanks very much for the information you sent me last autumn (October 4, 1973). Someone went to a lot of trouble to copy these articles. Here comes some more money, and, also another request. . ."

"It has been my pleasure to have been a contributor to the Epilepsy Foundation of America for many years and I believe in the wonderful work being performed by the Foundation. And even though retired and living on a very limited income, my wife and I have always tried to make some contribution, such as the inclosed.

"Now we find out the reason for your work as we have a grandson age 5-1/2 years suffering with epileptic seizures, not serious at present by doctors opinion but becoming worse account of inability to ascertain the most effective medication and proper anti-convulsant drugs for a child of this age."

"Enclosed please find our check for \$5.00 to go towards the causes of epilepsy. We would like to have you send us all the latest information that you have on this illness . . . (description of son's epilepsy). Quite naturally as parents we are very much concerned and want to find for our boy all precautions available and any other information. We hope that you can be of assistance to us . . . Thank you for your prompt and kind attention to our concerns."

- # "Many thanks again for your generosity as well as your great interest in educating the citizens of our state -- not only those subject to seizures and their families but the public in general."
- # "The pamphlets you have sent me have enlightened me on the subject of epilepsy and given me new hope. I try not to be over protective with my daughter because of her seizures . . . I will send a donation to the EFA to help with its efforts to help others with this problem. Again, I thank you for your concern and the hope you have given me."

Comments from Major Donors

Mrs. Ellen R. Grass, Member of National Commission on Multiple Sclerosis; President, International Bureau for Epilepsy; Former Member, National Advisory Neurological Diseases and Stroke Council: "In my own case my gifts are given for specific purposes; I follow through in regard to implementation and I find Foundation records and responses of its executives meticulous in regard to the stewardship of my gifts."

Arnold Daum, Esquire; Cahill, Gordon, Sonnett, Reindel & Ohl, New York City: "As a regular donor to EFA, I have found great satisfaction in knowing my restrict gift has been utilized for the specific purpose intended. Through long service on the Board of Directors of EFA, I can also assure other donors of good use of their funds."

We have had questions from donors and in very few instances of which I am aware, were there further questions after we provided a copy of our Annual Report. But we agree that donors need all possible protection and it is our desire to provide every donor with information that will enable him to arrive at sound judgments.

9. SOME COMMENTS BY PARENTS OF CHILDREN WITH EPILEPSY

Parents are appreciative of the services available through the Foundation. Often they write to us with a feeling of despair, of not knowing where to turn for help. Our ability to provide reliable information, to refer them to clinics, hospitals or psycho/social facilities provides the right resource they desperately seek. Frequently, their contact with the local EFA chapter is the beginning point of the management of this disorder in their lives.

It is not unusual for us to receive letters of thanks from parents, such as those quoted below:

- # "I feel compelled to share with some of your readers our gratitude for the work done by Foundation members everywhere. . . . May God, with the help of the EFA, allow his life to continue in this manner."
- # "Thank you for your stand on the book The Terminal Man by Michael Crichton. I am the mother of a psychomotor epileptic child and was appalled at the grossly misleading statements made in this book. . . . You are brave and courageous people to take such a stand and I appreciate it very much."
- # "Somewhere a loved one or a friend has this condition. I wish each and every one of the readers of SPOKESMAN will open their hearts and pocketbooks to help the Epilepsy Foundation of America."
- # "As we have just learned that our 5-year old daughter has epilepsy, we would like to know as much as possible about the disorder. We would also like to be able to help and explain this as simply as possible to our daughter and also to understand it better ourselves. Would you therefore, send us any pamphlets or literature that you can as well as a list of books dealing with the subject of epilepsy."
- # "I received your literature yesterday and it was most timely. . . . I am certainly glad to find an organization that can help."

Parents are active in the epilepsy movement as well. There are parents on the National Board and chapters everywhere count them as active volunteers. Here are some remarks from three of them:

Frank Blair, Commentator for NBC-TV TODAY SHOW, Member of the National Board of Directors -- "By being active on the National Board of Directors of EFA, I have been able to do my part to encourage public understanding to ease the stigma and remove the fear and prejudice which surrounds this disorder. From time to time I have been able to speak publicly in major cities such as

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Boston and New York. In the long run, this will encourage public acceptance of the millions of persons with epilepsy, including my own daughter."

Fred Abrams, President of the Nassau County Chapter, Epilepsy Foundation of America, Hempstead, New York -- "I am a parent of a child with epilepsy. One obstacle to him leading a normal life is public ignorance and misinformation about this disorder. My being active with the Foundation both at the national level and at the local level is an investment in my child, his education, his acceptance by his peers and the potential of his future life because both levels are working to develop better public understanding."

Mary Miller, President of the Copper Chapter of Great Falls, Montana -- "Our son is fourteen years of age and has had epilepsy since birth. He is still having petite mal seizures which I assume may become grand mal. We were lacking in knowledge.

"My first opportunity came when Mr. Ross, the Regional Manager, came to Great Falls to organize a chapter. My sister, Senator Mansfield's assistant, saw a notice in the paper and called to advise me of the meeting. Some 80 persons attended and every one of them was overwhelmed because they learned more in that one meeting than they had ever known."

10. CITIZEN VOLUNTEERS NEED PROTECTION -- AND APPRECIATION --
AS WELL AS BENEFICIARIES AND CONTRIBUTORS

The key question here is "what makes a voluntary a voluntary?" More specifically, we could ask "why do people volunteer?" and "what is their role in American society?"

The concept of voluntarism in America has staffed fire departments, had a significant role in education, supported symphony orchestras, enabled major collections of paintings to be assembled, saved historic buildings, battled for the rights of trees, and helped servicemen in foreign lands. Without volunteers our major political parties and our entire political structure would simply cease to exist.

One has only to look at the intensive role played by volunteers in the field of health during the last 40 years to appreciate that the effort of volunteers and resultant government action has been the fulcrum which raised this country's health level to its present condition.

It is the voluntary in our society who becomes the advocate for his individual cause. In lawful cooperation with others who share his problems and views, he is free to form groups which will advance that view.

Mr. Paul D. Holland, President of EFA, has said it this way:

"A voluntary is an association of people who have a common lawful purpose to achieve, and who do not engage in the enterprise of the voluntary agency for any material gain ... The purpose of the voluntary is what the members decide it shall be. The value of that purpose is what those who support the cause and are recipients of its services deem it to be. They seek, in broad terms, to make a better society."

Mr. Holland touches here on a very pertinent point; that is, that there are at least three important roles in any voluntary movement -- the volunteer, the donor, and the beneficiary.

In the epilepsy movement, an even more important point may be that those three roles are frequently combined in the same person. The person who has epilepsy, or has experienced epilepsy in his family, is often the volunteer and the donor and the beneficiary of services. He knows the horror of the disorder in his life and therefore supports the one organization which has been acting on his behalf in all areas where that problem has disrupted his life.

As the American Institute of Certified Public Accountants has pointed out and EFA reported in its 1972 Annual Report:

"The value of services provided by most voluntary health and welfare organizations cannot be quantitatively measured by monetary data contained in financial statements."

It is the volunteers time, effort and talent donated to solving the problems which epilepsy has created that is EFA's greatest financial contribution. It cannot be bought, it can only be given ... voluntarily.

As clearly established in our April 5th statement, the Epilepsy Foundation of America absolutely and forthrightly supports the efforts of the Subcommittee to initiate legislation which will clarify the function and operation of all health voluntaries, which will provide a single unified reporting system, which will open to the public, as EFA always has, a full disclosure of all operations and data. But, at the same time, there is a responsibility to make all the facts known, to protect the rights of all individuals involved in voluntaries, remembering that the volunteer, the donor and the beneficiary are inextricably bound together with a unique sense of loyalty and sense of purpose.

We are determined, moreover, as we know you are, that the hearings fully illuminate a major national health problem and the activities of those working to alleviate it.

The millions of people with epilepsy and the thousands working in their behalf who are in fact, EFA, deserve no less.

11. ATTACHMENTS AND ADDITIONAL BIBLIOGRAPHY

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SURVEILLANCE OF ANTI-CONVULSANT TREATMENT BY HOME EEG MONITORING

Reginald C. Rickford* — EFA Research Grant
 Robert R. Myers** — EFA Fellowship
 James J. Stockard* — EFA Fellowship
 John A. Casler* — EFA Fellowship
 John Brism* — EFA Fellowship
 Huang H. Aung*

During the last ten years, it has become possible to transmit and process the EEG with wide separation of the subject and the computer. Thus, in 1963, an averaged EEG response generated by a patient in England was processed in Minneapolis [1]. More recently the feasibility of carrying out similar studies from the home with direct connection to a home telephone line has been demonstrated [2]. These studies demonstrated that while short term monitoring (i.e. five to 15 minutes) was quite feasible, there were often difficulties in long term monitoring caused by electrical noise from household appliances such as vacuum cleaners, showers and electrical switches. In the present observation, the goal has been to provide an epileptic patient with a very simple means of coupling his EEG to the telephone line (acoustic coupling) which he could operate himself and which did not interfere appreciably with the functioning of the home telephone. There is the further requirement that a simple EEG recording harness be designed which the patient could apply himself without assistance from a technician or the family.

The purpose of such a device is to allow monitoring of the EEG in suitable epileptic patients under anticonvulsant treatment. The problem these patients face is a need for frequent visits to the outpatient department where their EEG is checked and they are observed for the development of drug toxicity. It was felt that such visits could be appreciably reduced by using the home sampled EEG. This would provide a measure of success in suppression of abnormalities by the anticonvulsant drug. In addition, shifts in the peak alpha frequency has been shown to be a sensitive index of central drug toxicity. Furthermore, the EEG taken under the stress situation of environmental stress as compared, for instance, with the EEG laboratory would be more meaningful from the diagnostic standpoint.

SYSTEM

Figure 1 is a diagram of the overall system which includes: 1) a specially designed elastic head harness with seven-to-111 saline pool electrodes fabricated to suit the particular location of the patient's EEG abnormalities; 2) A bi-amplifier and modulation unit which transmits the EEG (by acoustic coupling) over a standard voice grade telephone line to the EEG laboratory; 3) At the EEG laboratory, the received signal is demodulated and monitored by

HOME TELEPHONIC EPILEPSY MONITORING TECHNIQUE

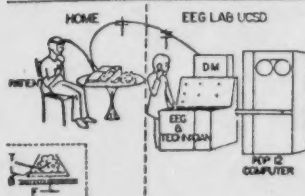


Figure 1. Diagram of the system. Insert of electrode detail: L-electrode lead, T-irrigation (saline) tube, B-elastic head band, F-fastener.

a technician before it enters the PDP-12 computer. The technician is in voice contact with the patient and may tell him to readjust the harness, to fill the electrodes, to relax, to open or close the eyes, etc. in order that a satisfactory recording is obtained. 4) The single channel EEG enters the PDP-12 computer in which it undergoes a power spectral analysis and an EEG spike count. 5) If the patient wishes, he can signal the technician by operating a switch on his home unit or he can lift the phone and talk with the technician directly.

This special head harness consists essentially of half inch diameter nipple attached by a fastener to an elastic headband. The nipples, which are 3/4 inch high, contain the silver electrode and a lead wire together with sponge packing which protrudes about 1/8 inch beyond the nipple opening. Covered into the nipple base is a polyethylene tube of about 1/8 inch length which ends in a color-coded needle syringe connector. This allows the patient to flush the electrode through the base of the nipple with saline by means of a syringe. In most instances, a three electrode system has been used and the patient, after he has placed the harness, proceeds to fill each electrode in turn till he feels the cool sensation of the injected saline on his scalp.

In practice, the patient is instructed to call the EEG laboratory at some predetermined time each day. After he has made contact, he puts on the head harness and fills the electrodes and then lowers the

University of California, San Diego
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 La Jolla, California 92037

Supported by USPHS Grant NS 08961-04 and the Epilepsy Society of America.

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DEPARTMENT OF NEUROSCIENCES
SCHOOL OF MEDICINE

LA JOLLA, CALIFORNIA 92037

5 April 1973

Fellowship Program
Epilepsy Foundation of America
1828 L Street, N.W.
Suite 406
Washington, D.C. 20036

RE: Annual Report on Fellowship Award--
James Stockard

Dear Sir:

This young man, who was supported for his summer work by the Epilepsy Foundation, has performed outstanding research in the general area of seizures related to surgical procedures. With the appearance of new surgical operations (such as coronary artery repair) which are carried out under cardiopulmonary bypass on older people, a new series of seizure problems has emerged. Another new source of seizure problems in the operating room has been the convulsive properties of a number of new anesthetic agents such as ketamine and ethrane. Jim Stockard has sought to bring some order out of this important but complex clinical area by the use of new monitoring methods developed in our laboratory. For this work, he has received two awards: 1) the student award of the Western EEG Society and 2) the Berger Award of the American EEG Society.

During his time of tenure of the epilepsy fellowship, Jim has been outstandingly productive and the following papers are either in press, published, or accepted for publication:

(over)

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Fellowship Program
Page 2
5 April 1973

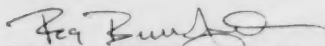
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With his abiding interest in epilepsy and drive to elucidate its mechanisms, Jim Stockard now wishes to be considered for a training grant which is the subject of a second letter. We greatly appreciate the Foundation's assistance in our research program. This inducement has kept Jim's efforts in the general area of epilepsy.

Sincerely,



Reginald G. Bickford, M.B., B.Chir., F.R.C.P.
Professor
Department of Neurosciences

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DEPARTMENT OF NEUROSCIENCES
SCHOOL OF MEDICINE

LA JOLLA, CALIFORNIA 92037

3 April 1973

CUTTING CONTENT

Fellowship Program
Epilepsy Foundation of America
1828 L Street, N.W.
Suite 406
Washington, D.C. 20036

RE: ROBERT R. MYERS

Gentlemen:

This letter is concerned with the application of Mr. Robert Myers, a graduate student in Bioengineering, for an epilepsy fellowship with the Epilepsy Foundation of America.

Perhaps initially I could recommend Bob by the enclosed letter which I wrote for him in support of his application to medical school.

I would like to strongly recommend consideration of Bob Myers for an epilepsy fellowship since he is an integral part of our research programs in the area of epilepsy. I believe we have an important monitoring method that could improve the treatment of epileptic patients significantly and I know that the provision of a fellowship would keep him active in the epilepsy area rather than some other field such as anesthesia. I think we would predict that your investment would produce very significant returns.

Sincerely yours,

Reginald G. Bickford, M.B., B.Chir., F.R.C.P.
Professor
Department of Neurosciences

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Enclosure

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LA JOLLA, CALIFORNIA 92037

5 April 1973

Fellowship Program
Epilepsy Foundation of America
1828 L Street, N.W.
Suite 406
Washington, D.C. 20036

RE: Annual Report on Fellowship Award--
John Brimm

Dear Sir:

John Brimm worked effectively in programming the PDP-12 computer during the winter months when he was a recipient of the fellowship award. John was successful in designing a program which computes the new compressed spectral array in much faster time than was previously possible. His new program allows us to compute two channels of EEG on-line which is a great advantage in clinical and experimental work. John Brimm's work specifically related to epilepsy has been in two areas: 1) in collaboration with Dr. Gose he has programmed the PDP-12 computer to recognize epileptic spike discharges based on their amplitude and slope properties. 2) John has been instrumental in developing the new type of home epilepsy monitor which allows the patient to self record his EEG and transmit it over a telephone line. The spikes in the patient's EEG have been recognized by the Brimm program and any effects of medication toxicity are detected by shifts in the alpha spectrum computed by his fast Fourier program. A list of John Brimm's publications is appended.

Our laboratory greatly appreciates the support we have had from the Epilepsy Foundation of America in these research studies. In the case of John Brimm, I am sure you will agree that your support was well rewarded.

Sincerely,

Reginald G. Bickford, M.B., B.Chir., F.R.C.P.
Professor
Department of Neurosciences

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Attachment

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DEPARTMENT OF NEUROSCIENCES
SCHOOL OF MEDICINE

LA JOLLA, CALIFORNIA 92037

April 19, 1974

Roger W. Buddington, Ph.D.
Institute Director
Epilepsy Foundation of America
1928 L. Street, N.W.
Washington, D.C. 20036

Dear Roger:

I was disturbed and amazed to hear that the Epilepsy Foundation has been criticized in Congress for its activities in funding epilepsy research. As you know the Foundation's activities both in research and in bringing its fruits to the notice of the general population, have long had my personal admiration. It is true that NIH wields far greater funds but it is also true that the humanistic touch which the Foundation brings to its much smaller research revenues makes them far more effective than their size might suggest. More specifically it is grossly unfair to criticize the article on telemetry of the EEG from the epileptic patient's residence which I gather was brought up for comment in the case against the Foundation. It is a fact that this research would not have been carried out without funds from the Foundation and that it is only indirectly related to parallel research which we are carrying out supported by NIH funds for pattern recognition. While the latter type of techniques were used to analyze information ducted in through the telephone lines, the idea and execution of the home monitoring did not have its origin in NIH sponsored research. Therefore, the Foundation was well justified in emphasizing its contribution in seeding this effort. Furthermore, I believe the Foundation has done important and essential work in interesting the general population in possibilities for improvement of the epileptic's lot by support of research in this area. This public relations work needs to be done since it recruits human effort and sympathy which is important to advance the general area of epilepsy research.

I would also like to comment on the very important seeding of talent achieved by its summer fellowships. It was because of such funding that our medical student, Jim Stockard became interested in epilepsy and spent the last two years working in this areas. During this time he has studied seizures occurring in the operating room and during anesthesia and has discovered an important modification in operative technique that reduces the incidence of seizures. During the time of this research he had no direct support from NIH. Jim Stockard is one of our most brilliant students and has won the Western EEG Society prize and also the Berger Award of the American EEG Society for his research. During the last two

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Dr. Roger Buddington
April 19, 1974
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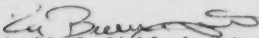
years he has published approximately 28 papers which is a good measure of the success of Foundation seeding activities.

Likewise Bob Myers, a Bioengineering student in our laboratory was attracted to research in epilepsy by his award of a summer fellowship. He is now pursuing research into the modulating influence of the cerebellum on seizure disorders. His work on epilepsy and related areas earned for him a student prize in a biomedical essay competition at the Minneapolis Meeting of the IEEE last year.

Your critics are certainly wide of the mark if they believe that the summer fellowships and other grants for research are ineffective in stimulating investigations in the field of epilepsy. Also, they fail to recognize the important motivating effect that commendation of research effort in local newspapers can have on the lives of these young investigators. I may say that they were both outraged when I told them about the recent criticism of the Foundation in the Congressional proceedings and they both said that they would write to you of their feelings.

If I can do anything personally to reinforce my own personal conviction that what the Foundation achieves in research is highly important and effective, I would be glad to do so.

Sincerely,


Reginald G. Bickford, M.B., B.Chir., F.R.C.P.
Professor

RGB:ark

LAW OFFICES
GORDON & HEALY
 1021 JEFFERSON PLACE, N. W.
 WASHINGTON, D. C. 20036

BEST COPY AVAILABLE

HAROLD GORDON
 ROBERT W. HEALY
 ROBERT R. REDMON
 ROBERT E. LEVINE

PAUL A. TOUSSAINT
 OF COUNSEL
 CABLE ADDRESS
 GORMIL
 (202) 788-8080

April 22, 1974

The Honorable Walter F. Mondale
 Chairman, Senate Subcommittee
 on Children and Youth
 127 C Street, N. E.
 Room 309
 Washington, D. C.

Attention: Harvey M. Katz, Esq.

Dear Senator Mondale:

As I advised Mr. Katz by telephone on Friday, the salary allocation sheets for Fiscal Year 1972 of the Epilepsy Foundation of America were found by H. Leroy Smith, Comptroller for the Foundation while searching through other material. We will be submitting to you shortly an affidavit from Mr. Smith regarding the circumstances under which he found this material which he had believed to be no longer in existence, the audit for that fiscal year having long since been completed.

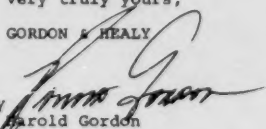
I have been advised that while searching through transfer files, Mr. Smith found the original of the attached sheets. They appear to be the allocations for wages done on a monthly basis with a final cumulative page.

When I was advised of this discovery, I requested that copies be made so that they could be immediately transferred to you and Mr. Katz.

Very truly yours,

GORDON & HEALY

By


 Harold Gordon

HG:to
 Enclosures

LAW OFFICES
GORDON & HEALY
 1021 JEFFERSON PLACE, N.W.
 WASHINGTON, D. C. 20038

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HAROLD GORDON
 ROBERT W. HEALY
 ROBERT R. REDMON
 ROBERT E. LEVINE

April 25, 1974

PAUL A. TOUSSAINT
 OF COUNSEL
 CABLE ADDRESS
 GORMIL
 (202) 785-8030

The Honorable Walter F. Mondale
 Chairman
 Senate Subcommittee on Children and Youth
 127 C Street, N.E.
 Room 309
 Washington, D.C.

Attention: Harvey M. Katz, Esq.

Dear Senator Mondale:

In line with the letter of April 22, 1974 from Harold Gordon, Esq. of this office to the attention of Harvey M. Katz concerning the salary allocation sheets for the fiscal year 1972 for the Epilepsy Foundation of America, there is transmitted herewith the Affidavit of H. Leroy Smith, Jr., Controller for the Foundation outlining the circumstances under which he discovered the existence of the allocation sheets and the action taken by him subsequent to their discovery.

Should you have any questions in connection with this matter, please communicate directly with this office.

Very truly yours,

GORDON & HEALY

Robert E. Levine

By
 Robert E. Levine

REL/ddt

Enclosure

A F F I D A V I T**BEST COPY AVAILABLE**

CITY OF WASHINGTON)
) ss:
 DISTRICT OF COLUMBIA)

H. Leroy Smith, Jr., being first duly sworn on oath according to law, deposes and says that:

1. I am Controller of the Epilepsy Foundation of America, 1828 L Street, N. W., Washington, D. C.

2. During the course of the hearings held by the Senate Subcommittee on Children and Youth, on April 8 and 9, 1974, I testified that I had not seen, in the Foundation's files, any document or schedule which listed employees and how their time or salary was allocated among the various accounting categories for the fiscal year 1972. Based upon ongoing searches of the Foundation's files both prior to and during the course of the hearings, I believed that any such records had not been retained by the Foundation.

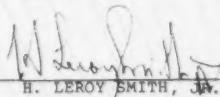
3. On the morning of April 19, 1974, while in the process of compiling financial data with respect to one of the chapters of the Epilepsy Foundation of America, I was reviewing the contents of a transfer file which presumably contained accounting records only from the years 1969 and 1970. During my perusal of these records I discovered for the first time the Foundation's salary allocation worksheets for the year 1972. I

-2-

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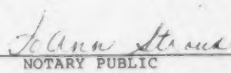
had no previous knowledge that these records which were requested by the Senate Subcommittee had been retained and misplaced in such a manner until I discovered their existence entirely by accident.

4. Since the time of discovering these records, the worksheets remained in my constant custody or control. I personally made full and complete Xerox copies of the worksheets and furnished a complete and accurate copy of said worksheets to General Counsel for the Epilepsy Foundation of America for transmittal to the offices of Senator Walter F. Mondale, Chairman, Senate Subcommittee on Children and Youth, on April 22, 1974.



H. LEROY SMITH, JR.
Controller
EPILEPSY FOUNDATION OF AMERICA

Subscribed and sworn to before me this 22 day of April, 1974.



NOTARY PUBLIC

[SEAL]

My Commission Expires January 31, 1978

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Suite 408 • 1028 L Street, N.W. • Washington, D. C. 20036 • (202) 263-2930

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MEMBERSHIP NATIONAL
CHAIRMAN

Jack Lasham

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George Gordon, Ph.D.
Lawrence E. Schlesinger, Ph.D.

 Rehabilitation
George Wright, Ph.D.

June 28, 1974

 The Honorable Walter F. Mondale
United States Senate
Washington, D.C.

Dear Senator Mondale:

We appreciate your holding the record open until this date so that we could submit an additional statement to the Senate Subcommittee on Children and Youth. The statement by our president, Paul D. Holland, is attached.

Mr. Holland is a volunteer unpaid member of our Board of Directors and the president of our organization. He has been involved with the epilepsy movement since 1963 at both the local chapter level in California and at the national level. He is a practicing attorney in the state of California.

As one of those who testified before your committee, let me express my personal appreciation for your consideration, and the cooperative attitude of the members of your staff in this worthwhile effort to shed light on this national need for examination of the charitable organizations in the health field.

Sincerely yours,

 Paul E. Funk
Executive Vice President

 PEF/smv
Enclosure

STATEMENT FROM
EPILEPSY FOUNDATION OF AMERICA

BY

PAUL D. HOLLAND, ESQ.
PRESIDENT

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(Mr. Paul D. Holland, a practicing attorney in California, is a volunteer unpaid member of the Epilepsy Foundation Board of Directors, and the President of EFA.)

The Epilepsy Foundation of America especially appreciates this opportunity to submit a concluding statement to the Senate Subcommittee holding these hearings because we feel that our organization has not been completely or adequately described and defined. It seems to me that two salient facts -- or problems -- have not emerged from our testimony.

First, the Epilepsy Foundation represents the hope -- and at present virtually the only hope -- for perhaps twelve million Americans who have a problem with epilepsy. These are those who are afflicted, and their families. At present, they have few places to turn, other than to us, for help -- to us, and to their doctors, for understanding.

Secondly, we have not made it abundantly clear that the present Foundation, even with what may be regarded as shortcomings, is a working, viable and really the only national mechanism and forum for those who are interested in solving the problems of epilepsy to learn, to share their knowledge, and into which to pour their voluntary efforts.

These two factors make it extremely important to the public that this Foundation, of which I am one of many dedicated volunteer members, be allowed to continue, be encouraged to continue its performance and that criticism of our efforts to knowledgeable, tolerant and kindly.

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Otherwise, what other solutions present themselves? Stop this effort and walk away from suffering people, 70 percent children? Or turn the whole effort over to the government, and the expense of the American taxpayer?

The Epilepsy Foundation of America, resulting from a merger of predecessor organizations, has been making steady progress since 1968 (as presented in previous documents) but we believe that these hearings have been helpful in

- 1) bringing our objectives and activities into sharper focus;
- 2) analyzing operations;
- 3) providing an opportunity for self-examination with the help of an outside view as expressed by the Subcommittee.

Since these hearings opened in February, 1974, our Board of Directors has been following the proceedings with great attention and as their president, I wish to submit this additional information on behalf of the Epilepsy Foundation of America.

I will not repeat the testimony which covers these efforts in some detail and also show how we raise funds to help the four million people with epilepsy. However, I would like to call attention to five areas of accomplishment, all of which have been on-going since 1968. There are many others as well but these I feel are most significant and are indicative of the progress which has been made.

- 1) Aiding in the changing of laws -- such as those having to do with employment, licensing, and insurance -- which adversely affect those with epilepsy and their ability to be self-supporting.

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- 2) The organization, development, training and support of a national chapter system, 160 in number in various stages of development, which through volunteer members, professional and lay, obtain and provide services at the hometown level for people with epilepsy and their families.
- 3) Bringing the technique of gas-liquid chromatography to the medical community (in terms of epilepsy) through 4 major research projects, seminars, support of training sessions, distribution of literature concerning GLC, development of standards for GLC, dissemination of reports concerning GLC to the medical community.
- 4) Providing the voice and presence of an advocate on behalf of the person with epilepsy to the many federal, state and local organizations (governmental, medical, psychological and social) to encourage and plead for recognition of the problem and various solutions. Our progress with those interested and involved in vocational rehabilitation services and programs in the state of Florida is an excellent example. The work of our people in staffing Developmental Disabilities Councils across the country is another.
- 5) The dissemination of public health information and education to eradicate misconceptions, explain the problems of epilepsy, provide knowledge to enable people to cope with the disorder has been implemented by the distribution of millions of booklets and pamphlets, 50,000 showings of television and radio spots, nearly a million copies of news releases plus press contacts to encourage the presenting of the epilepsy story as it really is, thousands of school alert kits have been issued to teachers and consequently

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have reached millions of school children in both urban and rural areas teaching them how to accept their fellow students who suffer from epilepsy. Thus we are combating prejudice at an early, learning stage in life.

The school alert type of approach has led to aggressive community efforts on the part of chapter volunteers to instruct others in what epilepsy is and how to deal with it. There have been excellent local programs, using materials provided by EFA headquarters, with public health authorities, nurses, police, fire and emergency crews. It is the kind of grass-root effort with headquarters guidance and support which has proved so effective.

Most recently, we have had some definite indication of progress. We would respectfully call your attention to the Gallup Poll information which was published nation-wide in May, 1974. The figures on national understanding are most revealing. (The quotations are from a Washington POST story of May 16. See Gallup Poll information on next page.)

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"25 YEARS LATER: A CHANGED PUBLIC OPINION ON EPILEPSY"

by George Gallup

"Princeton, N.J. -- Public enlightenment regarding health problems has grown at a rapid pace in recent years. For example, attitudes toward epilepsy -- a condition now afflicting an estimated two to three million persons* -- have undergone profound change over the last quarter-century.

"Twenty-five years ago, in 1949, 45 per cent of American adults believed that epileptics should not be discriminated against in terms of employment. Today, 81 per cent hold this opinion.

"In 1949, 24 per cent said they would object to having their children go to school or play with epileptic children. Today, only 5 per cent would object.

"In 1949, 13 per cent of persons interviewed thought epilepsy was a form of insanity. Today, the comparable proportion is only 2 per cent.

"Beginning in 1949, and at regular five-year intervals since that time, the Gallup Poll as a public service has conducted a national in-depth survey toward epilepsy for the National Institutes of Health in Bethesda.

* * * * *

"The survey also shows that a very high proportion of Americans, 94 per cent, have heard or read about epilepsy. Six in 10 (62 per cent) say they have known someone who has epilepsy, while six in 10 (60 per cent) also say they have seen a person having a seizure.

"Following are the principal findings showing the change since 1949:

*The Professional Advisory Board of the Epilepsy Foundation of America estimates that at least two percent of the present population of the United States, or a minimum of four million persons, suffer from some form of convulsive disorder.

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"Have you ever heard or read about the disease called epilepsy or convulsive seizures (fits)?"

	YES	NO
1949	92	8
1974	94	6

"Did you ever know anyone who had epilepsy?"

	YES	NO	NOT FAMILIAR WITH EPILEPSY
1949	57	35	8
1974	62	32	6

"Have you ever seen anyone who was having a seizure (fit)?"

	YES	NO	NOT FAMILIAR WITH EPILEPSY
1949	56	36	8
1974	60	34	6

"Do you think epileptics should be employed in jobs like other people?"

	YES	NO	DON'T KNOW	NOT FAMILIAR WITH EPILEPSY
1949	45	35	12	8
1974	81	8	5	6

"Would you object to having any of your children in school, or at play, associate with persons who sometimes had seizures (fits)?"

	YES	NO	DON'T KNOW	NOT FAMILIAR WITH EPILEPSY
1949	24	57	11	8
1974	5	84	5	6

"Do you think epilepsy is a form of insanity, or not?"

	YES	NO	DON'T KNOW	NOT FAMILIAR WITH EPILEPSY
1949	13	59	20	8
1974	2	86	6	6

The results are based on interviews with 1,504 adults, 18 and older, in more than 300 scientifically selected localities across the nation, conducted earlier this year."

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This Gallup Poll report is one clear indication of the success of the battle which has been waged concerning public attitudes about this very human problem. EFA has noted many times that the problem of social stigma for the person with epilepsy affects him daily -- in employment, schooling, family relationships, and every aspect of daily living. One of EFA's major objectives is a more empathetic public understanding and acceptance of these individuals as full members of society -- people whose disorder is now becoming controllable.

Volunteers are the heart of the organization, and are the citizens who deserve the public credit and thanks.

At the national level, EFA is managed and directed by a completely volunteer board, comprised of individuals of the highest character and reputation in their respective fields. It is a concerned board. Individual members are deeply involved in those areas of Foundation activity to which they can apply their expertise. They are reported to regularly by staff members and direct their various functions with serious, diligent concern. In fact, at the May, 1974, Board of Directors meeting, they authorized a management audit and review by a leading consultant. The best outside consultants are regularly used.

We believe the staff management of our organization is in capable hands. Again, we have always attempted to follow the best available standards as in regard to the classification of expenditures as provided by the National Health Council and the jurisdictions of 50 states and their attorneys general.

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When my predecessor as unpaid President, Mr. Paul E. Funk, became full-time chief executive officer, we instructed him to run a very tough and tight organization, which members of the board audit carefully and regularly. I believe our program is as well thought out as any such organization with which I have worked and I see steady improvement every year.

As to fund-raising, we all recognize the increased costs of any business operation. Inflationary pressures affect our organization as it does all others. In spite of these increased costs, we have set an objective of attaining a 19% fund-raising ratio within two years. This figure was established by vote of the EFA Executive Committee prior to the Subcommittee hearings and subsequently passed as a Board of Directors resolution. This ceiling is a combined national headquarters and chapters figure.

The anonymity which direct mail provides to donors appears to be one of the major factors in making direct mail the most effective method of raising funds for epilepsy. We have developed new mail criteria to answer criticisms which have been leveled at us. But, we have been hurt by reporting in the press and our contributions have dropped.

Consequently, this 19% fund-raising ratio presents EFA with a serious dilemma. By reducing fund-raising costs, a greater proportion of our income will be available to benefit the programs serving people with epilepsy; but when we reduce fund-raising costs, we will consequently reduce our income and have fewer total dollars available for programs and services.

This is a matter of major concern to us at EFA.

As an alternative, EFA and these people must turn to other sources for funds and assistance, perhaps the federal government.

Finally, let me respond to a key question from Senator Mondale during the hearings: "Where does a citizen go to find whether a voluntary charity is a reputable organization?"

I would raise an additional question: "What do we really mean by the term 'reputable'?"

These questions have been probed for more than twenty years by serious investigators in the field and no one has yet devised one set of standards which apply equally to all organizations serving different constituencies, in different kinds of work, facing different health problems, at different stages of their development.

Both the National Health Council and Council of Better Business Bureaus have attempted to be helpful, but they readily admit that they do not attempt to evaluate program effectiveness for the public for any of these organizations.

When it comes to information for the public -- we believe that any voluntary organization raising money from the public should be a prime source of honest, reliable information about its activities. At EFA, we openly present data and answer questions about all of our activities, including fund-raising.

We at EFA have come to the conclusion that one of the most pressing needs in the field of voluntary charitable health organizations -- the

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private sector's effort to help in this important work -- is the establishment of nation-wide standards of management, fund-raising and public reporting. We may well need a center of authority to which any citizen can direct inquiries about the organizations who are raising money for various health causes.

Many excellent organizations are local, or state, rather than national. Therefore, any regulatory effort must create uniform standards which will cover a rather wide spectrum of activities which meet many different requirements.

We at the Epilepsy Foundation will firmly support any efforts to establish a single, uniform, nation-wide set of standards for voluntary organizations which will serve not only the organizations in this field, but the donors and the recipients of our help.

In conclusion, I again wish to express the appreciation of the Board of Directors, the Professional Advisory Board and the staff of the Epilepsy Foundation of America to Senator Mondale, his colleagues and the staff of the Subcommittee for the effort they are making to bring public understanding and national cognizance to the effort being made in the voluntary health field.

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[Appendix 4. - Documents provided by officials of the States of Illinois, Michigan, and Pennsylvania]

Form 99-14

WILLIAM J. SCOTT
Attorney General, State of Illinois

Copy to Chicago 3635
1-28-72

(3126-10M-1-71)

PAGE 1

CO. 3635

ANNUAL REPORT-CHARITABLE ORGANIZATIONS

Report Form as required by Section 4(a) and (b) of the Illinois Charitable Solicitations Act.

Period beginning 1/1/71 and ended 12/31/71

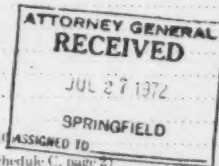
Name of Organization EPILEPSY FOUNDATION of AMERICA
Street and Number 1828 L Street, N. W., (Suite No. 406)
City and State WASHINGTON, D. C. Zip Code 20036

SUMMARY OF FINANCIAL ACTIVITIES

Enter "none" next to those items which are not applicable to the organization's financial activities. Round off to the nearest dollar.

PUBLIC SUPPORT & REVENUE

1. Contributions (including \$ -0- received in kind)	\$ 2,649,166
2. Capital funds campaign (including \$ - received in kind)	\$ -
3. Special events (after deducting \$ -0- for)	\$ -
4. Endowment gifts and bequests	\$ 1,000
5. Bequests other than endowment	\$ 100,785
6. TOTAL received directly (lines 1 to 5)	\$ 2,750,951
7. Indirect public support (Schedule A, page 2)	\$ 10,912
8. TOTAL public support (lines 6 and 7)	\$ 2,761,863
9. Fees and grants from government agencies	\$ 2,496
10. Other revenue (Schedule B, page 2)	\$ 8,979
11. TOTAL public support and revenue (lines 8 to 10)	\$ 2,773,338
12. Support and grants limited by donors or grantors (Schedule C, page 2)	\$ 48,183
13. Support and revenue available to finance current general activities (line 11 less line 12)	\$ 2,725,155



EXPENDITURES AND APPROPRIATIONS TO SPECIAL FUNDS

14. Program services	\$ 1,173,933
15. Management and general	\$ 331,910
16. Fund-raising: General support	\$ 1,155,036
17. Fund-raising: Capital funds campaign	\$ -0-
18. Major property and equipment acquisitions	\$ 19,713
19. Payments to affiliated organizations	\$ -0-
20. TOTAL expenditures (lines 14 through 19)	\$ 2,680,592
21. Deduction of expenditures financed by special funds (attach schedule)	\$ 42,337
22. Expenditures financed by current general revenue (line 20 less line 21)	\$ 2,638,255
23. Excess of (a) current general revenue over expenditures (line 13 less line 22), or (b) expenditures over current general revenue (line 22 less line 13)	\$ 86,900
24. Appropriations of General Revenue Funds	\$ -0-
25. Increase or decrease in unappropriated current general fund (line 23a less line 24 or line 24 less line 23a or line 23b plus line 24)	\$ 86,900

SEE INSTRUCTIONS

(827)

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PAGE 2

SCHEDULE A—INDIRECT PUBLIC SUPPORT

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1. Collections through local member units	\$ -0-
2. Contributions by associated organizations (less related fund raising expenses of \$ -0-)	\$ 10,309
3. Allocations by federated fund-raising organizations (less fund-raising expenses of \$ -0-)	\$ 603
4. Allocations by unassociated and non-federated fund-raising organizations	\$
5. TOTAL indirect public support (lines 1 to 4) to page 1, line 7	\$ 10,912

SCHEDULE B—OTHER REVENUE

1. Membership dues—individuals	\$ -0-
2. Assessments and dues—local member units	\$ -0-
3. Program service fees	\$ -0-
4. Net incidental revenue	\$
5. Sales and supplies to local member units (after deducting \$ -0- of direct costs and expenses)	\$ 860
6. Sales to public (after deducting \$ or direct costs and expenses)	\$ -0-
7. Investment income, gains and losses	\$ 6,196
8. Miscellaneous	\$ 1,923
9. TOTAL other revenues (lines 1 to 8) to page 1, line 10	\$ 8,979

SCHEDULE C—SUPPORT AND GRANTS LIMITED BY DONORS OR GRANTORS

1. Currently expendable, but only as specified by donor	\$ 47,183
2. Capital funds campaign and donations of major equipment	\$ -0-
3. Endowments not expendable; to be maintained for production of income	\$ 1,000
4. TOTAL support and grants limited by donor (lines 1 to 3) to page 1, line 12	\$ 48,183

	TOTAL	PROGR/	
		RESEARCH	PUBLIC HEALTH EDUCATION
1. Salaries	\$		
2. Employee health and retirement benefits			
3. Payroll taxes, etc.			
4. Total employee compensation			
5. Professional fees and contract service			
6. Supplies			
7. Telephone and telegraph			SEE ATTACHED
8. Postage and shipping			
9. Occupancy			
10. Local transportation			
11. Outside printing, art work, etc.			
12. Conferences, conventions, meetings and major trips			
13. Subscriptions and reference publications			
14. Specific assistance to individuals			
15. Membership dues and support payments			
16. Awards and grants (Attach Schedule)			
17. Equipment and other fixed assets			
18. Miscellaneous (Attach Schedule)			
19. TOTAL (of lines 4 to 18)	\$ 2,660,879	96,867	246,363

PAGE 4

CURRENT GENERAL FUND BALANCE SHEET

Assets

1. Cash	\$ 486,481
2. Accounts receivable	\$ 31,726
3. Pledges receivable (less allowance for uncollectible pledges of \$)	\$ -0-
4. Investments attach schedule	\$ 2,756
5. Fixed assets attach schedule (Separate Fund-See Schedule Attached)	\$ -0-
6. Inventory	\$ 71,952
7. Prepaid Expenses	\$ 24,106
8. Due from Restricted Funds	\$ 1,000
9. TOTAL (lines 1 to 8)	\$ 618,021

LIABILITIES AND FUND BALANCE

10. Accounts payable	\$ 288,691
11. Accrued Liabilities	\$ 20,958
12.	\$
13.	\$
14.	\$
15.	\$
16. TOTAL LIABILITIES	\$ 309,649

FUND BALANCE

17. Balance at beginning of year	\$ 221,472
18. Increase or decrease during year (line 25)	\$ 86,900
19. Balance at end of year (lines 17 and 18)	\$ 308,372
20. LIABILITIES AND FUND BALANCE (line 16 and 19)	\$ 618,021

NOTE: Attach balance sheets of other funds to this report. -See Attached Audit Report

Exhibit I.

CERTIFICATION BY CHARITABLE ORGANIZATION

We certify that the information furnished in this financial report, including continuation sheets, is true and correct to the best of our knowledge.

Signature of Pres. or Authorized Officer

Executive
DirectorTitle
Director of Adm.
and Finance.

Title

Date Signed

Date Signed

Signature of Chief Fiscal Officer

INDEPENDENT ACCOUNTANT'S OPINION

We have examined the balance sheet of Epilepsy Foundation of America at December 31, 1971 and the related summary of financial activities for the year then ended contained in this report. Our examination was made in accordance with generally accepted auditing standards and accordingly included such tests of the accounting records and such other auditing procedures as we considered necessary in the circumstances as further described in the following paragraph.

It was impracticable for us to extend our examination of contribution revenues received from the public beyond accounting for amounts so reported. The accompanying statements do not include the accounts of affiliated organizations.

In our opinion, the accompanying balance sheet and summary of financial activities present fairly the financial position of Epilepsy Foundation of America at December 31, 1971, the change in its fund balance and the results of its operations for the year then ended, in conformity with generally accepted accounting principles applied on a basis consistent with that of the preceding year and are in the form required by the Attorney General, State of Illinois. This report is prepared on the accrual accounting method.

Our examination was made primarily for the purpose of forming our opinion on the financial statements referred to in the preceding paragraph taken as a whole. We also examined the supplementary information, presented on Schedules F and G, and the Analysis of Functional Expenditures, by similar auditing procedures. In our opinion, this supplementary information, which is not essential for a fair presentation of financial position and results of operations, is stated fairly in all material respects in relation to the financial statements, taken as a whole.

Name of firm Price Waterhouse & Co.

Address Washington, D. C.

Signature

Title

Dated February 23, 1972

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EPILEPSY FOUNDATION OF AMERICA ATTACHMENT TO FORM CS-14 1971

TYPE	Year of Acquisition	Useful Life	Acquisition Cost	Additional		
				First Year Depreciation	Current Year Depreciation	Accumulated Depreciation
Office Furniture and Equipment	1968	- 0 -	- 0 -	- 0 -	- 0 -	- 0 -
" "	1969	5 - 10 years	\$ 9,518.66	- 0 -	\$ 1,477.44	\$ 3,645.14
" "	1970	5 - 10 years	\$ 13,741.68	- 0 -	\$ 1,606.20	\$ 1,817.01
" "	1971	5 - 10 years	\$ 19,712.68	- 0 -	\$ 675.69	\$ 675.69
TOTAL			\$ 42,973.02	- 0 -	\$ 3,759.33	\$ 6,137.84

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EPILEPSY FOUNDATION of AMERICA
ATTACHMENT to FORM CS - 14
1971

1. GRANTS and TRANSFERS to AFFILIATES AND
OTHER CHARITABLE ORGANIZATIONS.

<u>RECIPIENT</u>	<u>ACTIVITY</u>	<u>AMOUNT</u>
Dallas Epilepsy Association Dallas, Texas	Program Grant	\$ 4,655
Greater NYC Chapter - EFA New York, N. Y.	General Operating	25,000
Greater Atlanta Chapter - EFA Atlanta, Georgia	" "	787
Syracuse Chapter - EFA Syracuse, N. Y.	" "	1,420
Sarasota Council on Epilepsy Sarasota, Florida	Donor Restricted Gift	200
National Childrens Rehabilitation Center Leesburg, Va.	General Operating	320,000

TOTAL GRANTS to AFFILIATES and other CHARITABLE ORGANIZATIONS \$ 352,062

2. LISTING OF EMPLOYEES EARNING IN EXCESS OF \$20,000 PER ANNUM

Executive Vice President	\$ 50,000.
Executive Director	27,500.
Deputy Director of Administration and Finance	23,500.
Deputy Director of Program Services and Chapter Devel.	21,200.
Director of Information and Education	20,000.
Director of Administration	22,100.

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EPILEPSY FOUNDATION OF AMERICA
STATE OF ORGANIZATION

SECURITIES SCHEDULE

Date Acquired	TYPE AND NAME OF SECURITY	INVENTORY BEGINNING OF PERIOD		PURCHASES OR OTHER ACQUISITIONS			SALES OR OTHER DISPOSITIONS			Net Gain or Loss
		Shares or Principal	Cost or Acquisition Value	Shares	Cost	Market Value	Shares	Price	Market Value	
1959	Phila Electric Co. Common Stock	50	1,200.00				50	22.258	1112.90	11/
1969	U.S. Gypsum Co. Common Stock	2	137.00				7	62.705	438.94	11/
1968	IBX - Common Stock	4	1,436.00	5	38.812	294.06	4	294.99	1179.58	11/
1970	Sandix Corp. Common Stock	25	1,275.00				25	53.02	1450.50	11/
1970	Lauter Chemicals Common Stock	100	2,575.00	150	31.25	4687.50	250	36.049	9012.25	11/
1970	IBX - Common Stock	1	298.30	1	294.99	294.99	2	24.99	565.93	11/
1970	C.S. - Common Stock	100	2,950.00				100	42.698	4269.28	11/
1970	Capitol Building Corp. Common Stock	20	500.00	20	3.625	872.50	20	37.753	755.05	11/
1970	U.S. Savings Bond	1	75.00	2	150.00	300.00	2	0.31	23.62	11/
1970	Kenton Corp. Common Stock	2	33.75	3	56.00	168.00	3	42.746	128.24	11/
1971	J.C. Penny Common Stock									
1971	Columbia Gas System Common Stock									
5/71	Mass. Investors Trust	35	37.25	1303.75			35	31.058	1087.05	11/
12/71	Eastman Kodak	120	15.00	1800.00			120	13.013	1561.60	11/
12/71	Control Data-Common Stock	12	95.00	1140.00						
		8	46.00	368.00						
Note		All acquisitions were acquired as contributions. No securities were purchased with Foundation								
TOTALS			10,480.25						21,666.39	

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Form 99-34

WILLIAM J. SCOTT
Attorney General, State of Illinois

10000-200-0-70

PAGE 1

CO.3535

ANNUAL REPORT-CHARITABLE ORGANIZATIONS

Report Form as required by Section 4(a) and (b) of the Illinois Charitable Solicitations Act.

Period beginning 1/1/72 and ended 12/31/72

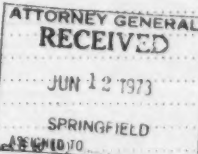
Name of Organization Epilepsy Foundation of America
 Street and Number 1828 L Street, N.W., Suite 406
 City and State Washington, D.C. Zip Code 20036

SUMMARY OF FINANCIAL ACTIVITIES

Enter "none" next to those items which are not applicable to the organization's financial activities. Round off to the nearest dollar.

PUBLIC SUPPORT & REVENUE

1. Contributions (including \$-0- received in kind)	\$ 3,088,147
2. Capital funds campaign (including \$ received in kind)	\$ none
3. Special events (after deducting \$ for)	\$ none
4. Endowment gifts and bequests	\$ 11,000
5. Bequests other than endowments	\$ 33,915
6. TOTAL received directly (lines 1 to 5)	\$ 3,133,062
7. Indirect public support (Schedule A, page 2)	\$ 79,321
8. TOTAL public support (lines 6 and 7)	\$ 3,212,383
9. Fees and grants from government agencies	\$ 7,941
10. Other revenue (Schedule B, page 2)	\$ 5,008
11. TOTAL public support and revenue (line 8 plus line 10)	\$ 3,226,332
12. Support and grants limited by donors or grantors (Schedule C, page 2)	\$ 54,619
13. Support and revenue available to finance current general activities (line 11 less line 12)	\$ 3,161,713



EXPENDITURES AND APPROPRIATIONS TO SPECIAL FUNDS

14. Program services	\$ 1,521,544
15. Management and general	\$ 362,163
16. Fund-raising: General support	\$ 1,274,171
17. Fund-raising: Capital funds campaign	\$ none
18. Major property and equipment acquisitions	\$ 24,949
19. Payments to affiliated organizations	\$ none
20. TOTAL expenditures (lines 14 through 19)	\$ 3,182,827
21. Deduction of expenditures financed by special funds: (attach schedule)	\$ 48,886
22. Expenditures financed by current general revenue (line 20 less line 21)	\$ 3,133,939
23. Excess of (a) current general revenue over expenditures (line 13 less line 22), or, (b) expenditures over current general revenue (line 22 less line 13)	\$ 26,774
24. Appropriations of General Revenue Funds	\$ none
25. Increase or decrease in unappropriated current general fund (line 23a less line 24 or line 24 less line 23a or line 23b plus line 24)	\$ 26,774

SEE INSTRUCTIONS

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PART 2

SCHEDULE A—INDIRECT PUBLIC SUPPORT

1. Collections through local member units	\$	
2. Contributions by associated organizations (less related fund raising expenses of \$ -0-)	\$	79,321
3. Allocations by federated fund-raising organizations (less fund-raising expenses of \$)	\$	
4. Allocations by unassociated and non-federated fund-raising organizations	\$	
5. TOTAL indirect public support (lines 1 to 4) to page 1, line 7	\$	79,321

SCHEDULE B—OTHER REVENUE

1. Membership dues—individuals	\$	
2. Assessments and dues—local member units	\$	
3. Program service fees	\$	
4. Net incidental revenue	\$	
5. Sales and supplies to local member units (after deducting \$ of direct costs and expenses)	\$	
6. Sales to public (after deducting \$ or direct costs and expenses)	\$	
7. Investment income, gains and losses	\$	2,789
8. Miscellaneous	\$	3,219
9. TOTAL other revenues (lines 1 to 8) to page 1, line 10	\$	6,008

SCHEDULE C—SUPPORT AND GRANTS LIMITED BY DONORS OR GRANTORS

1. Currently expendable, but only as specified by donor	\$	54,619
2. Capital funds campaign and donations of major equipment	\$	
3. Endowments not expendable: to be maintained for production of income	\$	11,000
4. TOTAL support and grants limited by donor (lines 1 to 3) to page 1, line 12	\$	64,619

	TOTAL	PROGR	
		Research	Public Health Education
1. Salaries	\$		
2. Employee health and retirement benefits			
3. Payroll taxes, etc.			
4. Total employee compensation			
5. Professional fees and contract service			
6. Supplies			
7. Telephone and telegraph			
8. Postage and shipping			
9. Occupancy			
10. Local transportation			
11. Outside printing, art work, etc.			
12. Conferences, conventions, meetings and major trips			
13. Subscriptions and reference publications			
14. Specific assistance to individuals			
15. Membership dues and support payments			
16. Awards and grants. (Attach Schedule)			
17. Equipment and other fixed assets			
18. Miscellaneous. (Attach Schedule)			
19. TOTAL (of lines 4 to 18)	\$ 3,157,878	175,498	245,738

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PAGE 3

SCHEDULE D—PROFESSIONAL FUND RAISERS AND SOLICITORS

Names and addresses of Fund-Raisers.

(Attach Schedule if Additional Space is required)

AMOUNT RECEIVED

1. none \$
2. \$
3. TOTAL (lines 1 and 2) \$
4. If professional solicitors were used in a fund raising campaign, attach a list of solicitors and the amount of their compensation.
5. If expenses were paid to professional fund raisers in addition to compensation, state amount \$
6. Did either professional fund raisers or professional solicitors handle receipts? Yes ☐ No ☒

SCHEDULE E—GENERAL INFORMATION

1. If any transfers were made to other charitable organizations or affiliated or associated organizations, attach a Schedule showing the amount of transfer and the reason for the transfer.
2. The books and financial records of the organization are maintained on a cash ☐ accrual ☒ or other ☐ basis.
3. How much of your program benefits Illinois residents? (Estimate if you lack accurate figures) ^{estimated} \$53,770 % 3.6
4. Are there any employees of your organization who earn over \$20,000 per year? (Attach list) Yes ☒ No ☐
5. Are there any changes in your registration statement (form CO-1)? Yes ☐ No ☒ (Attach list)
6. Does your organization use volunteer help? (See item F of general rules) Yes ☐ No ☒

ANALYSIS OF FUNCTIONAL EXPENDITURES

SERVICES (Identify By Name)			SUPPORTING SERVICES		
Professional Educ. & Training	Community Services	Patient Services	Management and General	FUND RAISING	
				General Support	Capital Funds Campaign
See Attached Audit Report Exhibit V					

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PAGE 1 CURRENT GENERAL FUND BALANCE SHEET

Assets	
1. Cash	\$ 492,422
2. Accounts receivable	\$ 177,682
3. Pledges receivable (less allowance for uncollectible pledges of \$)	\$
4. Investments—attach schedule	\$ 22,846
5. Fixed assets—attach schedule	\$ 53,747
6. Inventories (at cost)	\$ 69,133
7. Other assets	\$ 17,292
8.	\$
9. TOTAL (lines 1 to 8)	\$ 833,222

LIABILITIES AND FUND BALANCE	
10. Accounts payable	\$ 347,277
11. Other liabilities (principally salaries)	\$ 27,225
12.	\$
13.	\$
14.	\$
15.	\$
16. TOTAL LIABILITIES	\$

FUND BALANCE	
17. Balance at beginning of year	\$
18. Increase or decrease during year (line 25)	\$
19. Balance at end of year (lines 17 and 18)	\$ 458,720
20. LIABILITIES AND FUND BALANCE (line 16 and 19)	\$ 833,222

NOTE: Attach balance sheets of other funds to this report. (See attached Audit Report, Exhibit III)

CERTIFICATION BY CHARITABLE ORGANIZATION

We certify that the information furnished in this financial report, including continuation sheets, is true and correct to the best of our knowledge.

Paul G. Smith
Signature of Pres. or Authorized Officer

Executive
Vice President
Title
May 24, 1973
Date Signed

Signature of Chief Fiscal Officer

Title
Date Signed

REPORT OF INDEPENDENT CERTIFIED PUBLIC ACCOUNTANTS

We have examined the accompanying balance sheets of the various funds of

as of _____, and the related summary of financial activities for the year then ended. Our examination was made in accordance with generally accepted auditing standards, and accordingly included such tests of the accounting records and such other auditing procedures as we considered necessary in the circumstances.

In our opinion the balance sheets mentioned above present fairly the financial position of

as of _____ and the changes in its fund balances for the year then ended, and the above mentioned summary of financial activities presents fairly the public support and revenue and the expenditures and appropriations of special funds for the year then ended in conformity with generally accepted accounting principles applied on a basis consistent with that of the preceding year and are in the form required by the Attorney General, State of Illinois. This report is prepared on the _____ cash, _____ accrual, or _____ (other) accounting method.

The accompanying supplementary information identified as Schedules A, B, C, and Analysis of Functional Expenditures have been subject to the test and other auditing procedures applied in the examination of the financial statements mentioned above and, in our opinion, is fairly stated in all respects material in relation to the financial statements taken as a whole.

Dated _____, Name of firm _____
Address _____
Signature _____
Title _____

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STATE OF MICHIGAN
DEPARTMENT OF ATTORNEY GENERALSTANLEY D. STEINBORN
Deputy Attorney GeneralFRANK J. KELLEY
ATTORNEY GENERALLANSING
48913

April 5, 1974

RECEIVED
SENATOR MUNDALE
APR 5 2 16 PM '74

The Honorable Walter F. Mondale
The United States Senate
The Capitol
Washington, D.C.

Dear Senator Mondale:

In Michigan, the charitable solicitations licensing law is administered by the Attorney General. My office has established guidelines for implementing this statute. You have asked about our experience with the Epilepsy Foundation of America.

That Foundation applied for a license to solicit donations within this state in 1973. Based on the information provided by the Foundation, including a financial statement for the period ending December 31, 1962, prepared by Price, Waterhouse & Company, my office denied the application for a license to solicit charitable funds in Michigan. Our decision was based on three concerns.

First, the Foundation did not meet our requirement that it must have an agent located in Michigan since it was organized and is operated out-of-state.

Second, the Foundation did not disclose the salaries paid to the ten highest officials working outside the state, and the salaries for the five highest paid officials working within the state. This also violates our guidelines for licensure.

Third, we determined from the Foundation's application and financial statement that only 48 percent of the revenues collected were actually spent on the charitable purposes for which it was created. In Michigan, we generally require that a charitable organization must spend at least 70 percent of its revenues for the charitable program. Anything less than this, we feel, is a misleading and deceptive practice.

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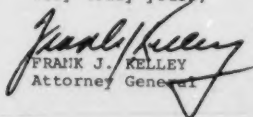
Hon. Walter F. Mondale
Page 2
April 5, 1974

After this denial, the Foundation named a Michigan agent, submitted a listing of the salaries required, and submitted a statement outlining special facts and circumstances supporting a lower percentage for the charitable program.

After reviewing this application and financial data, a license was then authorized for the Epilepsy Foundation of America. It is an annual license which expires October 24, 1974.

Enclosed is a copy of Michigan's guidelines. If you need additional information, please do not hesitate to contact me.

Very truly yours,


FRANK J. KELLEY
Attorney General

Enclosure

38-970 297

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Standards of Licensure Under
Act 68, PA 1915 as amended

When reviewing financial statements and accompanying information pursuant to Act 68, PA 1915, as amended to determine whether there is sufficient evidence for licensure to publicly solicit charitable donations or memberships, the following standards will be applied:

A solicitation license shall not be issued unless:

1. The applicant in the prior accounting period has expended 70% or more from donation or membership income for its charitable purposes, except as provided in standard number 4.
2. The applicant has not unreasonably accumulated income, except where the accumulation has been approved by a court having jurisdiction over the applicant, or where it is demonstrated the accumulation is for the purpose of capital expansion to take place within a reasonable future time.
3. The applicant has not conferred emoluments or other benefits upon any officer, employee, or trustee apart from salaries, which are excessive.
4. The expected fund raising and administrative costs are not excessive in relation to the expected gross amount to be raised. Where such cost exceeds 30% of the expected gross receipts, they shall be considered excessive unless special facts or circumstances are presented showing that a cost higher than 30% are not excessive.
5. The applicant has made a reasonable apportionment of expenditures between fund raising, administration and charitable purposes.
6. The charitable purposes for which donations or memberships are received have been carried out.

7. All the solicitation materials, appeals or advertisements of the applicant are framed in such a manner as not to be fraudulent, deceptive or misleading to the public.
8. The applicant has not expended a substantial part of its assets for the purpose of attempting to influence legislation, carrying on a political campaign or has otherwise engaged in political propaganda.
9. The applicant, or any officer, agent, servant, employee, director or trustee has not engaged in any fraudulent, misleading or deceptive practice in connection with the solicitation of donations or memberships from the public.

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DEPARTMENT OF ATTORNEY GENERAL

CHARITABLE TRUST DIVISION

SECTION OF LICENSE TO SOLICIT FUNDS

For Calendar Year 1972 or other fiscal yearbeginning January 1, 1972 and ending December 31, 1972

SCHEDULE OF SALARIES PAID TO OFFICERS, DIRECTORS OR TRUSTEES

EPILEPSY FOUNDATION OF AMERICA
Name of the Organization

1828 L Street, N.W.	Washington, D. C.	20020
Address	City	State zip code

List of the Ten highest paid officers OUTSIDE OF MICHIGAN:

Name:	Address:	Salary Paid
Paul E. Funk	Washington, D. C.	\$ 41,993.63
Thomas M. Ennis	" "	26,166.73
James A Shannon	" "	23,451.27
Robert E. Moore	" "	21,981.47
Don L. Organ	" "	20,730.01
Ronald I. Personett	" "	19,150.95
Joseph J. Rizzo	" "	17,551.62
Melba Gandy	" "	15,070.59
Margaret M. Paul	" "	14,931.75
William N. Brown	" "	14,701.56

List of the Five highest paid officers INSIDE OF MICHIGAN:

none		

Date: _____

Signature _____

SCHEDULE A
(Form 990)

 Department of the Treasury
 Internal Revenue Service

Organizations Exempt Under 501(c)(3)
Supplementary Information

▶ Attach to Form 990.

For calendar year 1971 or fiscal year

beginning 1 Jan. 1971, and ending 31 Dec. 1971

1971

 Name **EPILEPSY FOUNDATION of AMERICA** Employer identification number **52-0856660**
Part III Compensation of Officers, Directors and Trustees

Name and address	Social security number	Title	Time devoted to position	Compensation
Paul E. Funk 1659 32nd Street, N. W., Washington, D.C.	296-07-5717	Exec. Vice President	107%	\$50,000

 Total—Enter here and on line 11, Part II, Form 990 **\$50,000**
Part IV Compensation of Five Highest Paid Employees (Other than included in Part I—see instructions)

Name and address of employee paid more than \$30,000	Social security number	Title	Compensation
NONE			

 Total number of other employees paid over \$30,000 **0**
Part V Five Highest Paid Persons for Professional Services (See instructions)

Name and address of person paid more than \$30,000	Type of service	Compensation
NONE		

 Total number of others receiving over \$30,000 for professional services **0**
Part VI

1. During the taxable year, has the organization (1) attempted to influence any national, State, or local legislation, or (2) participated or intervened in any political campaign? **X**
- If "Yes," attach a detailed description of such activities and copies of any materials published or distributed by the organization in connection with such activities.
2. Has the organization received a ruling or determination letter from the Internal Revenue Service that it is not a private foundation within the meaning of section 509(a)? **X** **10/20/70**
- If "Yes," enter date of ruling or letter.
3. Is the organization a private foundation? (See instructions for definition) **X**
- If "No," complete Part V on page 2. If "Yes," complete and attach Schedule B (Form 990).

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EX. #1

AN ACT

(Act #337 of 1963, As Amended
By Act #246 of 1972.)

Relating to Charitable organizations; requiring the registration of such organizations; and regulating the solicitation of money and property by or on behalf of charitable organizations as amended in 1972.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. The act of August 9, 1963 (P.L.628), known as the "Solicitation of Charitable Funds Act," is amended by adding a section to read:

Section 1.1. Legislative Intent. — It is the intention of the Legislature that this shall not be a mere registry statute but an act intended not only to require proper registration of charitable organizations, professional fund-raisers and professional solicitors but also to regulate the soliciting of money and property by or on behalf of charitable organizations, professional fund-raisers, professional solicitors and to require proper accounting for the use and distribution of said funds.

Section 2. Definitions. — As used in this act:

(1) "Charitable organization" means a person which is or holds itself out to be a benevolent, educational, philanthropic, humane, patriotic, religious or eleemosynary organization or any person which solicits or obtains contributions solicited from the public for charitable purposes after the effective date of this act. A chapter, branch, area, office or similar affiliate or any person soliciting contributions within the Commonwealth of Pennsylvania for a charitable organization which has its principal place of business outside the Commonwealth shall be a charitable organization for the purposes of this act. This definition shall not be deemed to include duly constituted religious organizations or any group affiliated with and forming an integral part of said organization no part of the net income of which inures to the direct benefit of any individual and which have received a declaration of current tax exempt status from the government of the United States: Provided, That no such affiliated group shall be required to obtain such declaration if the parent or principal or organization shall have obtained same.

(2) "Contributions" means the promise or grant of any money or property of any kind or value.

(3) "Department" means the Department of State.

(4) "Federated fund raising organization" means a federation of independent charitable organizations which have voluntarily joined together, including but not limited to a United Fund or Community Chest, for purposes of raising and distributing money for and among themselves and where membership does not confer operating authority and control of the individual agencies upon the federated group organization.

(5) "Parent organization" is that part of a charitable organization which coordinates, supervises or exercises control over policy, fund-raising, and expenditures, or assists or advises one or more chapters, branches or affiliates in the Commonwealth.

(6) "Person" means any individual, organization, trust, foundation, group, association, partnership, corporation, society, or any combination of them.

(7) "Professional fund-raising counsel" means any person who for a flat fixed fee under a written agreement plans, conducts, manages, carries on, advises or acts as a consultant, whether directly or indirectly, in connection with soliciting contributions for, or on behalf of any charitable organization but who actually solicits no contributions as a part of such services. A bona fide salaried officer or employe of a charitable organization maintaining a permanent establishment within the Commonwealth shall not be deemed to be a professional fund-raising counsel.

(8) "Professional solicitor" means any person who, for a financial or other consideration, solicits contributions for, or on behalf of a charitable organization, whether such solicitation is performed personally or through their agents, servants or employes or through agents, servants or employes specially employed by, or for a charitable organization, who are engaged in the solicitation of contributions under the direction of such person, or a person who plans, conducts, manages, carries on, advises or acts as a consultant, *whether directly or indirectly*, to a charitable organization in connection with the solicitation of contributions but does not qualify as "professional fund-raising counsel" within the meaning of this act. A bona fide *full-time* salaried officer or employe of a charitable organization maintaining a permanent establishment within the Commonwealth shall not be deemed to be a professional solicitor.

No attorney, investment counselor or banker, who advises any person to make a contribution to a charitable organization, shall be deemed, as the result of such advice, to be a professional fund-raising counsel or a professional solicitor.

(9) "Commission" means the Commission on Charitable Organizations herein created.

(10) "*Solicitation*" means *the asking, seeking, appealing, requesting, directly or indirectly by means of mail, personal contact, written material, radio, television, news media, magazines or other periodicals or any other means of communication, of money or property of any kind or value or pledges for the same.*

Section 3. Registration of Charitable Organizations. - (a) Every charitable organization which intends to solicit contributions within this Commonwealth, or have funds solicited on its behalf, shall, prior to any solicitation, file a registration statement with the department upon forms prescribed by the commission, which shall be good for one full year and which shall be refiled in the next and each following year in which such charitable organization is engaged in solicitation activities. It shall be the duty of the president, chairman or principal officer of such charitable organization to file the statements required under this act. Such statements shall be sworn to and shall contain the following information:

(1) The name of the organization and the purpose for which it was organized.

(2) The principal address of the organization and the address of any offices in this Commonwealth. If the organization does not maintain an office, the name and address of the person having custody of its financial records.

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(3) The names and addresses of any chapters, branches or affiliates in this Commonwealth.

(4) The place where and the date when the organization was legally established, the form of its organization, and a reference to any determination of its tax exempt status under the Internal Revenue Code.

(5) The names and addresses of the officers, directors, trustees and the principal salaried executive staff officer.

(6) A copy of a balance sheet and income and expense statement audited by an independent public accountant for the organization's immediately preceding fiscal year, or a copy of a financial statement audited by an independent public accountant covering, in a consolidated report, complete information as to all the preceding year's fund-raising activities of the charitable organization, showing kind and amount of funds raised, costs and expenses incidental thereto, and allocation or disbursement of funds raised.

(7) Whether the organization intends to solicit contributions from the public directly or have such done on its behalf by others.

(8) Whether the organization is authorized by any other governmental authority to solicit contributions and whether it is or has ever been enjoined by any court from soliciting contributions.

(9) The general purpose or *purposes for which the contributions to be solicited shall be used.

(10) The name or names under which it intends to solicit contributions.

(11) The names of the individuals or officers of the organization who will have final responsibility for the custody of the contributions.

(12) The names of the individuals or officers of the organization responsible for the final distribution of the contributions.

(a.1) The Secretary of the Commonwealth or his designee shall examine each initial application of charitable organizations for the right to solicit funds and each renewal application of charitable organizations for the right to solicit funds and if found to be in conformity with the requirements of this act and all relevant rules and regulations it shall be approved for registration. Any applicant who is denied approved registration may, within fifteen days from the date of notification of such denial, request in writing a hearing before the commission, which hearing shall be held within fifteen days from the date of the request.

(b) Each chapter, branch or affiliate, except an independent member agency of a federated fund-raising organization, may separately report the information required by this subsection, or report the information to its parent organization which shall then furnish such information as to its Pennsylvania affiliates, chapters and branches in a consolidated form to the department. An independent member agency of a federated fund-raising organization, as hereinbefore defined, shall comply with the provisions of this act independently, unless specifically exempted from doing so.

(c) The registration forms and any other documents prescribed by the commission shall be signed by an authorized officer or by an independent public accountant and by the chief fiscal officer of the charitable organization and shall be verified under oath.

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(d) Every charitable organization which does not engage a professional solicitor or professional fund-raising counsel, expends less than seven per cent of the contributions received for administration purposes and submits (an independent) a proper registration to the department shall pay an annual registration fee of ten dollars (\$10). (a) Every other charitable organization which submits a proper registration to the department shall pay an annual registration fee of twenty-five dollars (\$25) if the charitable organization solicits and receives gross contributions from the public of twenty-five thousand dollars (\$25,000) or less during the immediate preceding fiscal year. Every charitable organization which submits a proper registration to the department shall pay an annual registration fee of one hundred dollars (\$100) if the charitable organization solicits and receives gross contributions in excess of twenty-five thousand dollars (\$25,000) during the immediate preceding fiscal year. A parent organization filing on behalf of one or more chapters, branches or affiliates and a federated fund-raising organization filing on behalf of its member agencies shall pay a single annual registration fee for itself and such chapters, branches, affiliates or member agencies included in the registration statement.

(e) Both the chapter, branch, area office or similar affiliate soliciting in this Commonwealth as well as the parent of a charitable organization which has its principal place of business outside of the Commonwealth shall be subject to all of the provisions hereof.

(f) Upon receipt of a request from the Secretary of the Commonwealth or upon its own initiative the commission shall make or cause to be made such investigation of any applicant as it shall deem necessary. As a result of its investigation and action, the commission shall certify to the Secretary of the Commonwealth its approval or disapproval of the application. No applicant shall be approved if one or more of the following facts is found to exist:

(1) That one or more of the statements in the application are not true.
 (2) That the applicant is or has engaged in a fraudulent transaction or enterprise.

(3) That a solicitation would be a fraud upon the public.

(4) That solicitation and fund-raising expenses (including not only payments to professional solicitors, but also payments to professional fund-raisers, and internal fund-raising and solicitation salaries and expenses) during any of the three years immediately preceding the date of application have exceeded thirty-five per cent of the total moneys, pledges, or other property raised or received by reason of any solicitation and/or fund-raising activities or campaigns. As used in this subsection, the term "internal fund-raising and expenses" shall include, but not be limited to, such portions of the charitable organization's salary and overhead expenses as were fairly allocable (on a time or other appropriate basis) to its solicitation and/or fund-raising expense. In the event special facts or circumstances are presented showing that expenses higher than thirty-five per cent were not unreasonable, the commission has the discretion to allow such higher expense.

(5) That the expected cost of solicitation and fund-raising expenses for the specific year in which the application is submitted (including not

only payments to professional solicitors, but also payments to professional fund-raisers, and internal fund-raising and solicitation salaries and expenses) will exceed thirty-five per cent of the total money, pledges or other property to be raised or received by reason of any solicitation and/or fund-raising activities or campaigns. As used in this subsection, the term "internal fund-raising and expenses" shall include, but not be limited to, such portions of the charitable organization's salary and overhead expenses as will be fairly allocable (on a time or other appropriate basis) to its solicitation and/or fund-raising expense. In the event special facts or circumstances are presented, showing that expenses higher than thirty-five per cent will not be unreasonable, the commission has the discretion to allow such higher expense.

(6) That such activities to be financed will be incompatible with the health, safety or welfare of the citizens of the Commonwealth of Pennsylvania.

Section 4. Certain Persons and Organizations Exempt from Registration.-

(a) The following charitable organizations shall not be required to file an annual registration statement with the department:

(1) Educational institutions, the curriculums of which in whole or in part are registered or approved by the State Council of Education of the Commonwealth of Pennsylvania, either directly or by acceptance of accreditation by an accrediting body recognized by the State Council of Education: Provided, That such educational institutions simultaneously file with the Commission on Charitable Organizations duplicates of such annual fiscal reports as are filed with the Department of Public Instruction of the Commonwealth of Pennsylvania.

(2) Persons requesting contributions for the relief of any individual specified by name at the time of the solicitation when all of the contributions collected without any deductions whatsoever are turned over to the named beneficiary for his use.

(3) Charitable organizations which do not intend to solicit and receive and do not actually raise or receive contributions from the public in excess of two thousand dollars (\$2,000) during a calendar year or do not receive contributions from more than ten persons during a calendar year, if all of their functions, including fund-raising activities, are carried on by persons who are unpaid for their services and if no part of their assets or income inures to the benefit of or is paid to any officer or member. Nevertheless, if the contributions raised from the public, whether all of such is or is not received by any charitable organization during any calendar year, shall be in excess of two thousand dollars (\$2,000), it shall, within thirty days after the date it shall have received total contributions in excess of two thousand dollars (\$2,000), register with a report to the department as required by this act.

(4) Hospitals which are nonprofit and charitable and are required by law to file financial reports at least annually with the Auditor General of the Commonwealth of Pennsylvania: Provided, That a copy of the annual fiscal report so filed is also filed simultaneously with the Commission on Charitable Organizations.

(5) Organizations which solicit only within the membership of the organization by the members thereof.

The term "membership" shall not include those persons who are granted a membership upon making a contribution as the result of solicitation.

(6) A local post, camp, chapter or similarly designated element or a county unit of such elements of a bona fide veterans' organization which issues charters to such local elements throughout this State, a bona fide organization of volunteer firemen, a bona fide ambulance association or bona fide rescue squad association or a bona fide auxiliary or affiliate of any such organization, provided all its fund-raising activities are carried on by members of such an organization or an affiliate thereof, and such members receive no compensation directly or indirectly therefor.

(b) Any charitable organization claiming to be exempt from the registration provisions of this act and which is about to or does solicit charitable contributions shall submit, annually, to the department on forms to be prescribed by the commission the name, address and purpose of the organization and a statement setting forth the reason for the claim for exemption. If exemption, the department shall issue, annually, a letter of exemption which may be exhibited to the public. No registration fee shall be required of any exempt organization.

Section 5. Commission on Charitable Organizations. - (a) The Commission on Charitable Organizations, herein referred to as the "commission," shall consist of seven members, one of whom shall be the Secretary of the Commonwealth or his designate, who shall be the chairman, one of whom shall be the Attorney General or his designate, one of whom shall be the Secretary of Public Welfare or his designate and one of whom shall be the Secretary of Health or his designate and three members to be appointed by the Governor.

(b) The commission shall have the power, and its duty shall be to promulgate rules and regulations and prescribe forms for registration or other purposes consistent with the specific requirements of this act and, after due notice to and consultation with representatives of charitable organizations, professional fund-raising counsel and professional solicitors and an opportunity for all such to be heard to make effective such rules, regulations, forms and procedures and when necessary to hold hearings and make adjudications as provided in this act and make recommendations to the Attorney General for enforcement of this act.

Section 6. Section 6 subsection (a) of section 8 of the act are amended to read:

Section 6. Limitations on Amount of Payments for Solicitation or **Fund-Raising Activities.** - (a) No charitable organization shall pay or agree to pay to a professional solicitor or his agents, servants or employees in the aggregate a total amount in excess of fifteen per cent (including reimbursement for expenses incurred and direct payment of expenses incurred) of the total moneys, pledges or other property raised or received by reason of any solicitation activities or campaigns.

(a.1) No charitable organization shall incur solicitation and fund-raising expenses (including not only payments to professional solicitors, but also payments to professional fund-raisers, and internal fund-raising and solicitation salaries and expenses) in excess of thirty-five per cent of total moneys, pledges or other property raised or received by reason of any solicitation, gift and/or fund-raising activities or campaigns. As used in this subsection, the term "internal fund-raising and expenses" shall include, but not be limited to, such portions of the charitable organization's salary and overhead expenses as are fairly allocable (on a time or other appropriate basis) to its solicitation and/or fund-raising expense. In the event special facts or circumstances are presented showing expenses higher than thirty-five per cent, the commission has the discretion to allow such higher funds and may impose such conditions as the commission or the Secretary of the Commonwealth shall deem necessary for such exemption.

(b) For purposes of this section, the total moneys, funds, pledges or other property raised or received shall not include the actual cost to the charitable organization or professional solicitor of goods sold or service provided to the public in connection with the soliciting of contributions.

(c) Every contract or written agreement between professional fund-raising counsel and a charitable organization shall be filed with the Secretary of the Commonwealth within ten days after such contract or written agreement is concluded.

(d) Every contract or a written statement of the nature of the arrangement to prevail in the absence of a contract between a professional solicitor and a charitable organization shall be filed with the Secretary of the Commonwealth within ten days after such contract or written agreement is concluded. If the contract or arrangement with a professional solicitor does not provide for compensation on a percentage basis, the commission shall examine the contract to ascertain whether the compensation to be paid in such circumstances is likely to exceed fifteen per cent of the total moneys, pledges or other property raised or received as a result of the contract or arrangement; if the reasonable probabilities are that the compensation will exceed fifteen per cent of the total moneys, pledges or other property, the secretary shall disapprove the contract or arrangement within ten days after its filing. No registered charitable organization or professional solicitor shall carry out or execute a disapproved contract, or receive or perform services, or receive or make payments pursuant to a disapproved contract. Any party to a disapproved contract shall, upon written request made within thirty days of disapproval, be given a hearing before the commission within thirty days after such request is filed.

Section 7. Limitation on Activities of Charitable Organizations. — No charitable organizations subject to this act shall solicit funds from the public except for charitable purposes or expended funds raised for charitable purposes for non-charitable purposes.

Section 8. Registration of Professional Fund-Raising Counsel and Professional Solicitor; Bonds; Records; Books. - (a) No person shall act as a professional fund-raising counsel or professional solicitor for a charitable organization subject to the provisions of this act, unless he has first registered with the department. Applications for such registration shall be in writing under oath or affirmation in the form prescribed by the department and contain such information as the commission may require. The application for registration by professional fund-raising counsel or professional solicitor shall be accompanied by an annual fee in the sum of *one hundred dollars (\$100)*. A partnership or corporation, which is a professional fund-raising counsel or professional solicitor, may register for and pay a single fee on behalf of all its members, officers, agents and employees. However, the names and addresses of all officers, agents and employees of professional fund-raising counsel and all professional solicitors, their officers, agents, servants or employees employed to work under the direction of a professional solicitor must be listed in the application.

(b) The applicant shall, at the time of making application, file with and have approved by the department a bond in which the applicant shall be the principal obligor in the sum of ten thousand dollars (\$10,000) with one or more sureties satisfactory to the department, whose liability in the aggregate as such sureties will at least equal the said sum and maintain said bond in effect so long as a registration is in effect. The bond shall run to the Commonwealth of Pennsylvania for the use of the department and any person who may have a cause of action against the obligor of said bonds for any losses resulting from malfeasance, nonfeasance or misfeasance in the conduct of solicitation activities. A partnership or corporation which is a professional fund-raising counsel or professional solicitor may file a consolidated bond on behalf of all its members, officers and employees.

(c) Each registration shall be valid throughout the Commonwealth for a period of one year and may be renewed for additional one year periods upon written application under oath in the form prescribed by the commission and the payment of the fee prescribed herein.

(d) The Secretary of the Commonwealth or his designate shall examine each application, and if he finds it to be in conformity with the requirements of this act and all relevant rules and regulations and the registrant has complied with the requirements of this act and all relevant rules and regulations, he shall approve the registration. Any applicant who is denied approved registration may, within fifteen days from the date of notification of such denial, request, in writing, a hearing before the commission, which hearing shall be held within fifteen days from the date of the request.

Section 9. Information Filed to Become Public Records. - Registration statements and applications, reports, professional fund-raising counsel contracts or professional solicitor contracts, and all other documents and information required to be filed under this act or by the department or by the

commission shall become public records in the office of the department, and shall be open to the general public for inspection at such time and under such conditions as the department may prescribe.

Section 10. Records to be Kept by Charitable Organizations, Professional Fund-raising Counsel and Professional Solicitors. — Every charitable organization subject to the provisions of this act shall, in accordance with the rules and regulations prescribed by the commission, keep true fiscal records as to its activities in Pennsylvania as may be covered by this act in such form as will enable it accurately to provide the information required by this act. Upon demand, such records shall be made available to the department, the commission or the Attorney General for inspection. Such records shall be retained for a period of at least three years after the end of the period of registration to which they relate.

Section 11. Reciprocal Agreements. — The department may enter into reciprocal agreements with the appropriate authority of any other state for the purpose of exchanging information with respect to charitable organizations, professional fund-raising counsel and professional solicitors. Pursuant to such agreements, the department may accept information filed by a charitable organization, professional fund-raising counsel or professional solicitor with the appropriate authority of another state in lieu of the information required to be filed in accordance with the provisions of this act, if such information is substantially similar to the information required under this act. The department shall also grant exemption from the requirement for the filing of annual registration statement with the department to charitable organizations organized under the laws of another state having their principal place of business outside the Commonwealth whose funds are derived principally from sources outside the Commonwealth and which have been granted exemption from the filing of registration statements by the state under whose laws they are organized if such state has a statute similar in substance to the provisions of this act.

Section 12. Prohibited Acts. — (a) No charitable organization, professional fund-raising counsel or professional solicitor, subject to the provisions of this act, shall use or exploit the fact of registration so as to lead the public to believe that such registration in any manner constitutes an endorsement or approval by the Commonwealth: Provided, however, That the use of the following statement shall not be deemed a prohibited exploitation "Registered with the Pennsylvania Department of State as required by law. — Registration does not imply endorsement of a public solicitation for contributions."

(b) No person shall, in connection with the solicitation of contributions for or the sale of goods or services of a person other than a charitable organization, misrepresent to or mislead anyone by any manner, means, practice or device whatsoever, to believe that the person on whose behalf such solicitation or sale is being conducted is a charitable organization or that the proceeds of such solicitation or sale will be used for charitable purposes, if such is not the fact.

(c) No person shall in connection with the solicitation of contributions or the sale of goods or services for charitable purposes represent to or lead anyone by any manner, means, practice or device whatsoever, to believe that any other person sponsors or endorses such solicitation of contributions, sale of goods or services for charitable purposes or approves of such charitable purposes or a charitable organization connected therewith when such other person has not given consent to the use of his name for these purposes; any member of the board of directors or trustees of a charitable organization or any other person who has agreed either to serve or to participate in any voluntary capacity in the campaign shall be deemed thereby to have given his consent to the use of his name in said campaign.

(d) No person shall make any representation that he is soliciting contributions for or on behalf of a charitable organization or shall use or display any emblem, device or printed matter belonging to or associated with a charitable organization for the purpose of soliciting or inducing contributions from the public without first being authorized to do so by the charitable organization.

(e) No professional solicitor shall solicit in the name of or on behalf of any charitable organization unless such solicitor has:

(1) Written authorization of two officers of such organization, a copy of which shall be filed with the department. Such written authorization shall bear the signature of the solicitor and shall expressly state on its face the period for which it is valid, which shall not exceed one year from the date issued.

(2) Such authorization with him when making solicitations and exhibits the same on request to persons solicited of police officers or agents of the department.

Section 13. Nonresident Charitable Organizations, Professional Fund-Raising Counsel and Solicitors, Designation of Secretary of the Commonwealth as Agent for Service of Process; Notice of Such Service by Attorney General.— Any charitable organization or professional fund-raising counsel or professional solicitor having its or his principal place of business without the Commonwealth, or organized under and by virtue of the laws of a foreign state, which or who shall solicit contributions from people in this Commonwealth, shall be subject to the provisions of this act and shall be deemed to have irrevocably appointed the Secretary of the Commonwealth as its or his agent upon whom may be served any summons, subpoena, subpoena duces tecum or other process directed to such charitable organization, professional fund-raising counsel or professional solicitor or any partner, principal officer

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or director thereof in any action or proceeding brought under the provisions of this act. Service of such process upon the Secretary of the Commonwealth shall be made by personally delivering to and leaving with him a copy thereof at the office of the Department of State in the City of Harrisburg, and such service shall be sufficient service provided that notice of such service and a copy of such process are forthwith sent by the Attorney General to such charitable organization or professional fund-raising counsel or professional solicitor by registered or certified mail with return receipt requested at its or his office, as set forth in the registration form required to be filed in the department pursuant to this act or in default of the filing of such form, at the last address known to the Attorney General or to the department.

Section 14. Enforcement and Penalties. - (a) If any charitable organization, professional fund-raising counsel or professional solicitor fails to file any registration application or statement, report or other information required to be filed by the department or the commission under this act, or otherwise violates the provisions of this act, the department shall notify the delinquent charitable organization, professional fund-raising counsel or professional solicitor by mailing a notice by registered or certified mail, with return receipt requested, to its or his last known address. If the required registration application or statement, annual report or other information is not filed or if the existing violation is not discontinued within two weeks after the formal notification or receipt of such notice, the commission may cancel, suspend the registration of such or refuse to accept delinquent charitable organization, professional fund-raising counsel or professional solicitor.

(b) The commission, upon its own motion or upon complaint of any person, may, if it has reasonable ground to suspect a violation, investigate any charitable organization, professional fund-raising counsel or professional solicitor to determine whether such charitable organization, professional fund-raising counsel or professional solicitor has violated the provisions of this act or has filed any application or other information required under this act which contains false or misleading statements. If the commission finds that any application or other information contains false or misleading statements, or that a registrant under this act has violated the provisions thereof, it may recommend to the department that the registration be suspended or cancelled and the department may so order.

(c) The registration of any charitable organization, professional fund-raising counsel or professional solicitor, which or who knowingly makes a false or misleading statement in any registration application or statement, report or other information required to be filed by the department or this act shall be revoked.

(d) All proceedings under this act shall be conducted in accordance with the Administrative Agency Law and all commission and department adjudications shall be subject to review and appeal as provided therein.

(e) In addition to the foregoing, any person who wilfully and knowingly violates any provisions of this act, or who shall wilfully and knowingly give false or incorrect information to the department in filing statements or reports

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required by this act, whether such report or statement is verified or not, shall be guilty of a misdemeanor, and, upon conviction thereof, shall be sentenced for the first offense to pay a fine of not less than one hundred dollars (\$100) and not more than five hundred dollars (\$500) or undergo imprisonment for not more than six months, or both, and for the second and any subsequent offense to pay a fine of not less than five hundred dollars (\$500) and not more than one thousand dollars (\$1000) or to undergo imprisonment for not more than one year, or both.

(f) Whenever the Attorney General or any district attorney shall have reason to believe or shall be advised by the Secretary of the Commonwealth (who shall have given due notice and full hearing to the charitable organization, professional fund-raiser or professional solicitor) that the said fund-raising counsel, charitable organization or professional solicitor is operating in violation of the provisions of this act or has knowingly and wilfully made any false statements in any initial or any renewal application to solicit or in any other information required to be filed by this act or whenever a charitable organization, professional fund-raising counsel or professional solicitor has failed to file a registration statement required by this act, or whenever there is employed or is about to be employed in any solicitation or collection of contributions for a charitable organization any device, scheme or artifice to defraud or to obtain money or property by means of any false pretense, representation or promise, or whenever the officers or representatives of any charitable organization, professional fund-raising counsel or professional solicitor have refused or failed after notice to produce any records of such organization, or whenever the funds raised by solicitation activities are not devoted or will not be devoted to the charitable purposes of the charitable organization, in addition to all other actions authorized by law, the Attorney General or district attorney may bring an action in the name of the Commonwealth of Pennsylvania against such charitable organization and its officers, such professional fund-raising counsel or professional solicitor or any other person who has violated this act or who has participated or is about to participate in any solicitation or collection by employing any device, scheme, artifice, false representation or promise, to defraud or obtain money or other property, to enjoin such charitable organization or professional fund-raising counsel or professional solicitor or other person from continuing such violation, solicitation or collection, or engaging therein, or doing any acts in furtherance thereof and for such other relief as to the court deems appropriate.

(g) The commission may refuse to grant an initial application to solicit, may refuse to renew an application and may revoke a registration of any charitable organization, professional fund-raising counsel or professional solicitor which or who knowingly makes a false statement in any initial registration application or renewal application or statement, annual report or other information required to be filed by the department or the act.

Section 15. Appropriation. — All fees shall be paid to the State Treasurer and are hereby appropriated to the Department of State for the ad-

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ministration and enforcement of this act.

The 1963 Act provided for the following repeals: (a) The act of May 13, 1925 (P.L. 644), entitled "An act relating to and regulating the solicitation of moneys and property for charitable, religious, benevolent, humane and patriotic purposes," and all acts amendatory thereof, are repealed.

(b) All other acts and parts of acts are repealed insofar as inconsistent herewith.

The 1963 Act was approved on August 9, 1963.

The amendment was approved on October 26, 1972.

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COMMISSION ON CHARITABLE ORGANIZATIONS
DEPARTMENT OF STATE
COMMONWEALTH OF PENNSYLVANIA

In re: :
: :
THE EPILEPSY FOUNDATION :
OF AMERICA :

BEFORE: Honorable Ronald Pettine (designee of Secretary of the Commonwealth), Honorable Max Leopold (designee of Secretary of Welfare), Honorable Richard J. Orloski (designee of the Attorney General), and Honorable Benjamin Bernstein (Public Member).

APPEARANCES:

Louis D. Apothaker, Esquire, Harold Gordon, Esquire,
For Applicants.

Robert J. Dixon, Deputy Attorney General for
Commission.

OPINION AND ORDER

Pursuant to Section 3(a.1) of the Solicitation of Charitable Funds Act, 10 P.S. § 160-3(a.1), the Epilepsy Foundation of America [hereinafter "EF of A"] requested a de novo hearing before the Commission On Charitable Organizations after being advised by the designee of the Secretary of the Commonwealth that the renewal application of EF of A. was being denied for exceeding the statutory limit of 35% placed on fund-raising costs under Section 6 (a.1) of the Act, 10 P.S. § 160-6. A hearing was conducted by

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the Commission on Tuesday, March 26, 1974, within 15 days of EF of A's request of March 13, 1974 as required by statute. At the hearing, EF of A. requested dual relief: 1) allow EF of A. to submit a consolidated report under Section 3 (b) of the Act, 10 P.S. § 160-3, wherein the EF of A. would register for itself and its 150 chapters, three of which are located in Pennsylvania, and 2) under the consolidated report -- or even under the original report -- the Commission exercise the discretion granted to it under Section 6(a.1) of the Act, 10 P.S. § 160-6 (a.3) and allow the EF of A. to exceed the statutory limitation of 35% on fund-raising costs.

After hearing all the evidence offered by EF of A. and oral argument thereon, the Commission makes the following findings of fact and conclusions of law.

FINDINGS OF FACT

1. In the original Annual Report upon which the designee of the Secretary of the Commonwealth based her denial, EF of A. stated to the Commission that its total of solicited contributions from the public for the fiscal year 1972 was \$3,133,062.

2. In the original Annual Report for fiscal year 1972, EF of A. stated to the Commission that its total solicitation fund raising expenses incurred in raising the \$3,133,062. from the public was \$1,274,171.

3. In view of the fact that EF of A. spent \$1,274,171. to raise \$3,133,062. from the public, EF of A's solicitation and fund-raising costs were 40.67% of the total moneys, pledges or other property raised or received by reason of any solicitation, gift and/or fund-raising activities.

4. EF of A. offered no evidence whatsoever indicating that the figures as originally presented to the designee of the

Secretary of the Commonwealth and thereafter to the Commission were erroneous or misleading.

5. In the second Annual Report for fiscal 1972 not offered to the designee of the Secretary of the Commonwealth but instead only offered directly to the Commission for the first time on Tuesday, March 26, 1974, EF of A. stated to the Commission that its consolidated report indicated the total solicited contributions for the national organization, and its 150 chapters (3 of which operate in Pennsylvania) was \$3,799,569.

6. In the second Annual Report (the consolidated report), EF of A. stated to the Commission that its total solicitation and fund-raising expenses incurred in raising the \$3,799,569. from the public was \$1,365,107.

7. In view of the fact that EF of A. spent \$1,365,107. in order to raise \$3,699,569. from the public, EF of A's consolidated solicitation and fund-raising costs were 35.93% of the total moneys, pledges or other property raised or received by reason of any solicitation, gift and/or fund-raising activities.

8. EF of A. stipulated that, even under the consolidated figures, it was exceeding the statutory limit of 35% imposed by Section 6 (a.1) of the Act, 10 P.S. § 160-6 (a.1).

9. In its second report (the consolidated report), EF of A., on behalf of itself and its affiliates, left blank 180 lines inquiring into the financial status of EF of A., including information regarding amounts spent on fund-raising for professional fees and services, postage, printing, conferences, salaries, supplies, etc.

10. In leaving 180 lines of financial information blank, EF of A. explained at footnote 5 that such information was unavailable and that EF of A. could not supply the requested information to the Commission.

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11. In the sworn testimony of the EF of A's accountant, the Commission was advised that EF of A's accounting firm, Price, Waterhouse & Co., could not supply such financial information because the affiliates did not supply the accountant with such information.

12. In testimony by counsel for EF of A., Harold Gordon, Esquire, it was stated that, historically, EF of A's fund-raising costs were in excess of 35%, and estimated to be in the range of 40% to 50%.

13. In testimony by counsel for EF of A., Harold Gordon, Esquire, it was stated that EF of A. could not guarantee the Commission that EF of A's fund-raising costs would come within 35% in the reasonably near future.

14. The second Annual Report (consolidated report) was statutorily deficient because EF of A., on behalf of itself and its affiliates, left blank 180 lines of relevant, material and pertinent information.

15. EF of A's testimony in support of its contention that its case involved special facts and circumstances within meaning of Section 6 (c.1) of the Act, 10 P.S. § 160-6 (a.1) by alleging that epilepsy is an unpopular disease to which people are reluctant to contribute was not persuasive, and the fact that it was able to raise in excess of \$3,000,000. in a single year indicates otherwise.

DISCUSSION

Section 3(b) of the Act, 10 P.S. § 160-3(b) gives national organizations which are not federated fund-raising organizations the option of filing a consolidated financial information form to the Commission. EF of A. is not a federated fund-raising organization, has 150 chapters, three of which are within Pennsylvania, and as such,

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clearly possesses the statutory right to file a consolidated report with the Commission. Section 3(a) of the Act, 10 P.S. § 160-3(a), unequivocally states, however, that the information filed shall be "...upon forms prescribed by the Commission...". If EF of A. desires to exercise its option of filing a consolidated report, it is also obligated by statute to make a complete disclosure of its financial picture by supplying all information required by the forms prescribed by the Commission. Submitting a consolidated report which leaves 180 blanks explaining that such information is not available does not meet the statutory requirements of registering under Section 3, 10 P.S. § 160-3. In view of the fact that the second Annual Report (consolidated report) is incomplete, as testified by EF of A's own accountant, and that such information shall not be forthcoming because even their own accountant does not have such information, the Commission has no other alternative but to reject the second Annual Report (consolidated report) as an incomplete submission, and, therefore, not properly before the Commission.

Given the fact that the second Annual Report (consolidated report) is wholly incomplete and not properly before the Commission, the only other report upon which the Commission can make its determination is the original Annual Report which has placed fund-raising costs at 40.67% of the amount of solicited contributions from the public. In addressing the rate of permissible solicitation and fund-raising costs, the statutory scheme is unequivocal:

"No charitable organization shall incur solicitation and fund-raising expenses... in excess of 35% of the total money, pledges, or other property raised or received by reason of a solicitation, gift and/or fund-raising activities or campaigns."

10 P.S. § 160-6 (a.1)

The legislative intent in enacting this provision is clear. Where a charity solicits money from the Pennsylvania public, the Legislature

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requires that, minimally, \$.65 out of every \$1.00 solicited goes to the charitable purpose as perceived by the donor. Our Legislature has decided that, for too long, too great a portion of fund-raising monies merely went back to self-perpetuating fund-raising schemes. Such is no longer the case in Pennsylvania.

EF of A. has never in the course of its testimony, either in its original Annual Report, or the consolidated Annual Report, indicated that it can or will abide by the statutorily imposed limit of 35%. Consequently, it has requested that the Commission exercise its discretion to allow higher fund-raising costs:

"In the event special facts or circumstances are presented showing expenses higher than 35%, the Commission has the discretion to allow such higher funds and may impose such conditions as the Commission or the Secretary of the Commonwealth shall deem necessary for such exemption."

No such facts or circumstances are presented in the case at bar. EF of A. is in violation of Pennsylvania law, and has not indicated that it is willing to abide by it. Based upon the evidence offered by the EF of A., the Commission finds that the facts of the instant case are not one which warrants an action of discretion by the Commission and the request for a special exemption is hereby denied.

CONCLUSIONS OF LAW

1. The original report showing fund-raising costs at 40.67% is properly before the Commission whereas the consolidated report is incomplete and not properly before the Commission.
2. The original report showing fund-raising costs at 40.67% conclusively demonstrates a violation of Pennsylvania's Solicitation of Charitable Funds Act, 10 P.S. § 160-6 (a.1).
3. EF of A's application for registration is disapproved because:

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- (a) in the three years preceeding registration, the application shows fund-raising costs in excess of 35% in violation of 10 P.S. § 160-3(f)(4);
- (b) in the specific year in which the application is submitted the testimony indicates that expected costs of fund-raising expenses will exceed 35% in violation of 10 P.S. § 160-3(f)(5); and
- (c) EF of A. is in violation of 10 P.S. § 160-6(a.1).

4. The facts of the case as presented by EF of A. do not persuade the Commission that this is an appropriate case of "special facts or circumstances" to allow EF of A. to circumvent the statutorily prescribed limits as set by our Legislature, and, therefore, the Commission denies the request for an exemption under 10 P.S. § 160-6(a.1).

ORDER

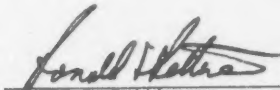
AND NOW THIS 28th DAY OF MARCH, 1974, IT IS HEREBY ORDERED AND DECREED by the unanimous vote of the Commission that Epilepsy Foundation of America's application for registration under the Charitable Solicitation Act, 10 P.S. 160-1 et seq. is hereby disapproved; and

IT IS FURTHER ORDERED AND DECREED that a certified copy of this Opinion and Order be directed to the Attorney General of the Commonwealth of Pennsylvania to seek all lawful means under Section 14 of the Act, 10 P.S. § 160-14, to secure compliance with this Order in the event that Epilepsy Foundation of America does not immediately cease and desist from any and all solicitation

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activities within the Commonwealth of Pennsylvania.

FOR THE COMMISSION:

A handwritten signature in dark ink, appearing to read "Ronald J. Pettine", is written over a horizontal line.

Ronald J. Pettine
Chairman

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February 1, 1974

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DEPARTMENT OF STATE

Ms. Carol Cochran
Director
Commission on Charitable
Solicitations
Department of State
Commonwealth of Pennsylvania
Harrisburg, Pennsylvania 17120

Re: Epilepsy Foundation of America,
Application for Certificate of Registration and
Annual Report

Dear Ms. Cochran

Enclosed please find an application and Parts I and II of the report noted above on behalf of the Epilepsy Foundation of America for whom I am general counsel.

I apologize for the late filing and we are in receipt of your letter of January 25, 1974 regarding this.

I appreciate your taking the time to discuss this matter with me by telephone today. As I indicated, the matter was delayed partially at Price Waterhouse, the accountants for the Foundation, and because of the difficulty of obtaining signatures of the appropriate officers.

It is my understanding that the Commonwealth of Pennsylvania has an allowable 35% fund raising cost. I believe that the Foundation is close to this figure. I hope that you will understand that this is a difficult disease entity to raise money for. Historically, for many years the Foundation

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Ms. Carol Cochran
February 1, 1974
Page 2

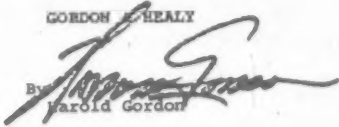
and predecessor organizations, as well as other organizations in the field, have been unable to raise any substantial funds in the field by low cost fund raising methods. There seems to be a general desire when giving to this disease entity to remain anonymous, and we have found that direct mail is the only successful method although at an admittedly higher cost factor than anyone would want to see. Testing has been going on for some time to lower these costs and I am able to state that the cost factor has gone down considerably in the last few years.

I should note that the figures in the report are solely for the national headquarters since the reporting shown apparently does not contemplate a consolidated report. Such a consolidated report showing both the national headquarters and the chapter combined, would indicate a fund raising cost ratio of less than 35%. The consolidated reporting method is what is shown in the Foundation Annual Report and is recommended by the National Health Council.

Should you have any questions on the report or the activities of the Foundation, please feel free to contact me and I will be glad to discuss them with you.

Very truly yours,

GORDON & HEALY

By 
Harold Gordon

HG:to
Enclosures

FORM CCO-168R
1963 Aug. 9, P.L. 638 (Act 237)
16 P.S. 168C1

COMMISSION ON CHARITABLE ORGANIZATIONS
COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF STATE



RENEWAL

APPLICATION FOR CERTIFICATE OF REGISTRATION - CHARITABLE ORGANIZATIONS

Application is hereby made in accordance with Solicitation of Charitable Funds Act.
(PLEASE TYPE OR PRINT IN INK)

DEVELOPED
2/25/74
BCE

1. Official name and address of organization to which correspondence should be mailed:
Epilepsy Foundation of America

(Full official name)

1828 L Street, N.W., Washington, D.C. 20036
(Street and number) (City) (State) (Zip Code)

2. If the name under which the applicant intends to solicit funds differs from the official name listed on Item 1, give the following information:

Name or Names, Other than Item 1, under which contributions will be solicited:	Reason for use of Name or Names
N/A	

3. Principal office: 1828 L Street, N.W., Washington, D.C. 20036
(Street and number) (City) (State) (Zip Code)

4. List all addresses of any offices in the Commonwealth: None

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FEB 6 1974

DEPARTMENT OF STATE

5. Name and address of the person having custody of its financial records:

Mr. Paul E. Funk 1828 L Street, N.W., Washington, D.C. 20036
(Name) (Street and number) (City) (State) (Zip Code)

6. Have you previously registered with the Commission on Charitable Organizations? Yes ☒ No ☐
If answer is YES, give name under which registered (if different from that shown in question 1), Same

Number 706 and date registered: December 11, 1972

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names and addresses. See Attached

8. Are you a parent organization or a federated fund raising organization, as defined in Section 2 (4) and (5) of the Solicitation of Charitable Funds Act? Yes _____ No X If YES, which? _____

9. Do you elect to file in a consolidated form as to your Pennsylvania affiliates, chapters or branches, or member agencies? Yes _____ No X

10. The form of the organization (check following as applicable)

Corporation

(a) Non-Profit X

(b) Business _____

Other (explain) _____

Individually

Trust _____

Foundation _____

Association _____

Partnership _____

11. When, where and how created: _____

12. Fiscal year of the applicant ends: December 31, 1973

13. Has any governmental agency determined that the applicant is tax exempt? Yes X No _____ If YES, attach copy of exemption letter (including that of the Internal Revenue Service) to this application unless previously furnished to the commission.

14. Has tax exemption been denied or cancelled at any time? Yes _____ No X If YES, attach copy of letter of denial.

15. Has the applicant, its professional fund raising counsel and/ or its professional solicitors been enjoined from soliciting contributions or are proceedings pending therefor? Yes _____ No X If answer is YES, give complete information.

16. Has an application, license, permit or registration of applicant, its professional fund-raising counsel and/ or its professional solicitors been denied or revoked by any governmental agency, or are proceedings pending therefor?

Yes X No _____ If answer is YES, give complete information. (Solicitation permit denied, Oakland, California, May 13, 1970, for failure to meet municipal code requirement that fund raising costs not be in excess of 16%)

17. Is applicant registered with or licensed by ANY other governmental agency for soliciting contributions inside or outside of Pennsylvania? Yes X No _____ If answer is YES, attach list with addresses. The Foundation conducts a national mail campaign. All necessary state registrations have been obtained or are pending.

18. Purpose for which applicant was originally organized and present purpose, if different: _____

See attached excerpts from Certificate of Incorporation

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19. General purpose or purposes for which the contributions shall be used: for the first time purposes
(see prior question) for which the Foundation was formed. The areas of expenditures
will be similar to those for last year (see financial report).
20. Total amount of funds proposed to be raised in Pennsylvania: \$3,870,000- Nationally Actual amount
raised last year? \$3,226,332- Nationally
21. What is estimated cost of raising such funds? \$1,400,000- Nationally Actual cost of raising
funds last year: \$1,274,171- Nationally
22. From the funds raised in Pennsylvania, how much do you intend to disburse in Pennsylvania to Pennsylvania recip-
ients? \$ unknown How much was so disbursed last year? \$ Disbursements not maint
by geographic locality
23. Applicant intends to solicit contributions (check all applicable):
- (a) By its employees X
- (b) By members or volunteers
- (c) Paid professional solicitors
- (d) Other (explain)
24. Outline in detail methods used in conducting solicitations, place of solicitation in Pennsylvania, etc. All funds
are to be raised in Pennsylvania by direct mail from the main office. This direct
mail campaign is national in scope.
25. If you use, or intend to use, Professional Fund Raising Counsel or Professional Solicitor, answer a, b, c and d below:
- | a. Name and Address of Professional Fund-Raising Counsel and/or Solicitor | Terms of Remuneration (as per contract) including beginning and ending dates |
|---|--|
| N/A | |
- b. Are all current contracts with Professional Fund-Raising Counsel or Professional Solicitor on file with the Commission on Charitable Organizations as required by Section 6 of the Solicitation of Charitable Funds Act? Yes No
- c. Has the Professional Fund-Raising Counsel or Professional Solicitor registered and filed a bond with this Department as required by Section 8 of the Solicitation of Charitable Funds Act? Yes No
- d. What is registration number of Professional Fund-Raising Counsel or Professional Solicitor:

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26. Names of individuals or officers of applicant who will have final responsibility for the custody of the control

NAME	TITLE
Mr. Paul E. Funk	Executive Vice President and Chief Exec. Officer

27. List ALL officers, directors, trustees, the principal salaried executive staff officer and officials in charge of overall direction, or management, including those who sign reports submitted to this Department, and those responsible for the final distribution of the contributions. (If not enough space below, use separate sheet). List the chief fiscal officer and his title first.

Name	Address	Title	Term (Ending Date)
Paul E. Funk	c/o Epilepsy Foundation of America	Ex. Vice Pres. & Chief Exec. Officer	Indefinite
James A. Shannon	c/o Epilepsy Foundation of America	Assoc. Ex. Director	Indefinite
See Attached List			

28. List on a separate sheet of paper the names of all employees involved in any activities whatsoever which pertain to or affect the raising of funds in Pennsylvania for applicant, total remuneration of each, and percentage of time each spent during last full year in matters pertaining to raising of funds (including membership drives). Any applicant using the system of Uniform Financial Reporting adopted by Volunteer Health and Welfare Organizations and referred to in the instructions need not answer this question 28.

We use the system of Uniform Financial Reporting and are members of the National Health Council

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INSTRUCTION— As required by Section 3 (c) of the Solicitation of Charitable Funds Act, this form shall be signed by the authorized officer of the organization or by the Independent Public Accountant and the chief fiscal officer of the Charitable Organization.

WE CERTIFY THAT THE INFORMATION FURNISHED IN THIS STATEMENT AND ALL CONTINUATION SHEETS IS TRUE AND CORRECT TO THE BEST OF OUR KNOWLEDGE, INFORMATION AND BELIEF.

x Thomas A. Neill Treasurer February 1, 1974
(Signature of Chief Fiscal Officer) (Title) (Date Signed)

Paul E. Funk Executive Vice President February 1, 1974
(Signature of Authorized Officer or Independent Public Accountant) (Title) (Date Signed)

AFFIDAVIT

~~CITY OF WASHINGTON~~
DISTRICT OF COLUMBIA
~~COUNTY OF WASHINGTON~~ CITY OF WASHINGTON

Thomas A. O'Neill, the chief fiscal officer,
and Paul E. Funk, (authorized officer or
independent public accountant) of Epilepsy Foundation of America, being duly sworn, depose
and say that they have both read the foregoing application and that they have verified all statements made herein and that
they are true and correct to the best of their knowledge, information and belief.

Sworn and subscribed to before me

this 1st day of February 1974
Jo Ann Strauss

My Commission Expires January 31, 1978

x Thomas A. Neill
Paul E. Funk
Chief Fiscal Officer
Authorized Officer or
Independent Public Accountant

PENNSYLVANIA CHAPTERS

ALLEGHENY PLATEAU CHAPTER

Epilepsy Foundation of America
5100 Center Avenue Suite 110
Pittsburgh, Pennsylvania 15232

EPILEPSY SOCIETY OF LYCOMING COUNTY

460 Market Street, Room 415
Williamsport, Pa. 17701

PHILADELPHIA CHAPTER

Epilepsy Foundation of America
Graduate Hospital
19th and Lombard Streets
Philadelphia, Pennsylvania 19146

U.S. DEPARTMENT OF JUSTICE
Washington, DC
20036

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PURPOSES FOR WHICH THE
CORPORATION WAS FORMED

(Excerpted from Article III,
Certificate of Incorporation,
filed 7 July 1967 with the
Secretary of State for the
State of Delaware)

1. To promote, conduct and support research into the causes and treatment of epilepsy;
2. To make known the available treatments for epilepsy;
3. To improve educational and vocational opportunities for persons with epilepsy;
4. To educate and provide information to the general public about epilepsy, with a view toward eradicating misconceptions about epilepsy;
5. To promote, establish, develop, maintain and conduct clinics, schools, camps and any other facilities or means for treating, educating, training, obtaining employment for, caring for, or in any other manner helping persons with epilepsy;
6. To encourage, foster and cause to be established chapters and affiliated organizations to assist in carrying out the purposes of the Corporation;
7. To cooperate and work with any health, welfare, educational or other organizations or groups having similar purposes or whose activities would further the purposes of the Corporation;
8. To provide financial support, by contributions, donations, grants or otherwise, to individuals, partnerships, corporations and other organizations engaged in activities that further any of the purposes of the Corporation; and
9. In general, to do all things necessary or convenient to effect any or all of the aforesaid purposes, to the extent permitted by law.

EPILEPSY FOUNDATION of AMERICA
Attachment to State of Pennsylvania
Form # CCO - 100R

*From 1972
application*

Item # 7 -- Affiliated Organizations in Pennsylvania.

1. Alleghany Plateau Chapter - EFA,
1017 Empire Building,
507 Liberty Avenue,
Pittsburgh, Pa. 15222.
2. Epilepsy Society of Lycoming County,
460 Market Street - #415,
Williamsport, Pa. 17701.
3. Philadelphia Chapter - EFA,
1700 Walnut Street - Suite 1014,
Philadelphia, Pa. 19103.

Item #16 -- Solicitation Licenses Denied.

Solicitation permits have been denied in the following municipalities for not meeting various statutory requirements:

1. City of Atlanta, Ga.
2. City of Indianapolis, Ind.
3. City of Los Angeles, Calif.
4. City of San Jose, Calif.
5. City of Oakland, Calif.
6. City of Tacoma, Washington.

Item #17 -- Solicitation Permits Granted

- | | |
|-------------------------|--------------------------------|
| 1. State of Connecticut | 8. State of Oregon |
| 2. " " Florida | 9. " " Oklahoma |
| 3. " " Georgia | 10. " " Virginia |
| 4. " " Illinois | 11. " " Wisconsin |
| 5. " " Minnesota | 12. District of Columbia |
| 6. " " New York | 13. City of Minneapolis, Minn. |
| 7. " " North Carolina | 14. " " Columbia, S. C. |

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PART I

For Year Ended Dec. 31 19 72

Legal Name of Organization Epilepsy Foundation of AmericaNumber and Street 1828 L Street, N.W.City and State Washington, D.C.Zip Code 20035

SUMMARY OF FINANCIAL ACTIVITIES

Enter "none" next to those items which are not applicable to the organization's financial activities.

PUBLIC SUPPORT AND REVENUE

1. Contributions (including \$ received in kind)	\$ 3,077,918
2. Capital funds campaign (including \$ received in kind)	-0-
3. Special events (after deducting \$ for)	-0-
4. Endowment gifts and bequests	11,000
5. Bequests other than endowments	44,144
6. TOTAL received directly (lines 1 to 5)	3,133,062
7. Indirect public support (Schedule A, page 2)	3,133,062
8. TOTAL public support (lines 6 and 7)	6,266,124
9. Fees and grants from government agencies	85,329
10. Other revenue (Schedule B, page 2)	3,226,332
11. TOTAL public support and revenue (lines 8 to 10)	9,577,785
12. Support and grants limited by donors or grantors (Schedule C, page 2)	65,619
13. Support and revenue available to finance current general activities (line 11 less line 12)	\$ 9,512,166

EXPENDITURES AND APPROPRIATIONS TO SPECIAL FUNDS

14. Program services (identify by name):	
(a) Research	\$ 175,498
(b) Public Health Education	245,738
(c) Professional Education and Training	126,326
(d) Community Services	902,452
(e) Patient Services	21,530
(f) TOTAL (lines 14a to e)	1,521,544
15. Management and general	\$ 362,163
16. Fund-raising: (a) General support	\$ 274,171
(b) Capital funds campaign	-0-
(c) TOTAL (lines 16a and b)	274,171
17. TOTAL supporting services (lines 15 and 16c)	1,635,334
18. Major property and equipment acquisitions	-0-
19. Payments to affiliated organizations	-0-
20. TOTAL expenditures (lines 14f, 17, 18 and 19)	3,157,878
21. Deduction of expenditures financed by special funds:	
(a) Special purpose funds	\$ 48,888
(b) Current restricted funds	
(c) Land, building and equipment funds	
(d) Funds functioning as endowment	
(e) TOTAL (lines 21a to d)	48,888
22. Expenditures financed by current general revenue (line 20 less line 21e)	3,108,990
23. Excess of (a) current general revenue over expenditures (line 13 less line 22), or	51,723
(b) expenditures over current general revenue (line 22 less line 13)	
24. Deduction of appropriations by board:	
(a) To special purpose funds	\$ 24,949
(b) To land, building and equipment funds	
(c) To funds functioning as endowment	
(d) TOTAL (lines 24a to c)	24,949
25. Increase in unappropriated current general fund (line 23a less line 24d), or	\$ 26,774
26. Decrease in unappropriated current general fund (line 24d less line 23a or line 23b plus line 24d)	

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Page 2

Schedule A—INDIRECT PUBLIC SUPPORT

1. Collections through local member units	\$
2. Contributions by associated organizations (estimated related fund-raising expenses \$)	
3. Allocations by federated fund-raising organizations (estimated related fund-raising expenses \$)	
4. Allocations by unassociated and non-federated fund-raising organizations	
5. TOTAL indirect public support (lines 1 to 4)—to Page 1, line 7	\$

Schedule B—OTHER REVENUE

1. Membership dues—individuals	\$
2. Assessments and dues—local member units	79,321
3. Program service fees	
4. Net incidental revenue	
5. Sales and supplies to local member units (after deducting \$ of direct costs and expenses)	
6. Sales to public (after deducting \$ of direct costs and expenses)	
7. Investment income, gains and losses	2,789
8. Miscellaneous	3,219
9. TOTAL other revenues (lines 1 to 8)—to Page 1, line 10	\$ 85,329

Schedule C—SUPPORT AND GRANTS LIMITED BY DONORS OR GRANTORS

1. Currently expendable, but only as specified by donor	\$ 54,619
2. Capital funds campaign and donations of major equipment	
3. Endowments not expendable; to be maintained for production of income	11,000
4. TOTAL support and grants limited by donor (lines 1 to 3)—to Page 1, line 12	\$ 65,619

ANALYSIS OF FUNCTIONAL EXPENDITURES

Use same names and classifications of program services as on lines 14 a to e page 1

1. Salaries	726,566
2. Employee health and retirement benefits	60,032
3. Payroll taxes, etc.	
4. Total employee compensation	786,598
5. Professional fees	80,253
6. Supplies	48,138
7. Telephone and telegraph	24,802
8. Postage and shipping	372,522
9. Occupancy	65,049
10. Outside printing, art work, etc.	150,503
11. Employment Costs	32,283
12. Conferences, conventions, meetings and major trips	169,483
13. Printing Materials & Services	667,485
14. Data Processing	191,162
15. Visual Aids	73,281
16. Awards and grants	446,876
17. Office Services	43,919
18. Miscellaneous	5,524
19. TOTAL (of lines 4 to 18)	3,157,878
20. Less directly related income	
21. TOTALS (line 19 less line 20)—must agree with amounts shown on line 14a to e, 15 and 16a and b, page 1	3,157,878

TOTAL	PROGRAM SERVICES	
	Research	Public Health Education
(a)	(b)	(c)
726,566	50,578	95,917
60,032	3,410	6,903
786,598	53,988	102,820
80,253	6,615	1,175
48,138	832	7,701
24,802	386	1,603
372,522	1,030	11,847
65,049	3,375	8,064
150,503	12,081	55,107
32,283		32
169,483	6,754	5,947
667,485		
191,162	489	1,594
73,281	409	39,255
446,876	86,806	1,473
43,919	686	8,018
5,524	47	1,102
3,157,878		
3,157,878	175,498	245,738

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Schedule D—PROFESSIONAL FUND RAISERS AND SOLICITORS

	NAMES AND ADDRESSES OF FUND-RAISERS OR SOLICITORS (Use footnote form if additional space is required)	AMOUNT ACCRUED		
		Fee (a)	Expenses (b)	Total (c)
1.	None	5		
2.				
3.				
4.				
5.				
6.	TOTAL (lines 1 to 5) (column (c) must agree with total of column (b) and (c), line 5 of Analysis of Functional Expenditures.)	5		

Schedule E—TRANSFERS TO AFFILIATED, ASSOCIATED OR CLOSELY RELATED ORGANIZATIONS

	NAMES AND ADDRESSES OF TRANSFERREES (Use footnote form if additional space is required)	PURPOSE OF TRANSFER	AMOUNT TRANSFERRED		
			Payment to Affiliates (a)	Grant or Expense (b)	Total (c)
1.	Nat'l Childrens Rehab. Center, Leesburg, Va. Support	Grant		270,000	270,000
2.	Dallas Epilepsy Assn., Dallas, Tex. Spec. Prog. Grant			11,927	11,927
3.	Greater N.Y.C., E.F.A., N.Y., N.Y. Spec. Prog. Grant			3,617	3,617
4.	Phila. Chapter, Phila., Pa. Spec. Prog. Grant			1,094	1,094
5.	TOTAL (lines 1 to 4) (column (a) must agree with line 19, page 1)		\$ -0-	286,638	286,638

1. Has the organization received or held during the year assets available to meet current expenditures, but only in compliance with restrictions specified by the contributors or grantors in writing? ☒ Yes ☐ No
2. Has the organization received, designated or held during the year any assets which are invested as income-producing securities or properties and only the income is available for current purposes? ☒ Yes ☐ No
3. Has the organization received, designated, or held during the year assets for acquisition, construction or replacement of land, buildings or equipment to be used in its regular activities, or does the organization own any significant amounts of land, buildings or equipment that it uses in its regular activities? ☐ Yes ☒ No
4. Was money or property received as a result of events or sales conducted by non-affiliated, non-associated or not closely related organizations? ☐ Yes ☒ No
- If yes, disclose, by footnote, the name(s) of the sponsoring organization(s), the nature of the sale(s) or event(s) and the terms of the agreement(s). ☐ Yes ☒ No

Professional Education & Training	(Identify By Name)			SUPPORTING SERVICES		
	Community Services	Patient Services	MANAGEMENT AND GENERAL	FUND-RAISING		
				General Support (a)	Special Projects Campaign (b)	
61,746	267,375	47,513	150,898	52,539		
4,762	18,882	3,130	19,232	3,713		
	286,257		170,130	56,252		
66,508						
679	20,471		38,968	10,345		
1,444	6,829	2,015	26,378	2,939		
838	16,930	887	3,421	737		
2,916	9,413	4,500	19,130	323,686		
5,327	21,366	2,334	14,593	9,990		
13,788	36,220	6,886	15,032	11,389		
	9,190		22,836	225		
12,780	123,412	3	18,492	2,095		
				667,485		
490	698	489	9,502	177,900		
6,676	24,482	131	1,937	391		
12,883	336,359		144	9,211		
1,958	9,040	3,639	20,220	358		
39	1,785	3	1,380	1,168		
126,326	902,452	71,530	362,161	1,274,171		

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CURRENT GENERAL FUND BALANCE SHEET

ASSETS		
1. Cash		\$ 421,331
2. Accounts receivable (less allowance for uncollectible accounts of \$)	5,012	177,682
3. Pledges receivable (less allowance for uncollectible pledges of \$)		
4. Marketable Securities, At Cost		22,946
5. Inventory of Mailing & Educational Materials, Cost		69,133
6. Prepaid		17,292
7.		
8.		
9. TOTAL (lines 1 to 8)		\$ 708,384

Liability and Fund Balances		
10. Accounts payable		\$ 347,277
11. Accrued Expenses, Principally Salaries		25,961
12.		
13.		
14.		
15.		
16. Fund balances		
17. SPECIAL PURPOSE FUNDS:		
18. Balance at beginning of year	\$ -0-	
19. Appropriated during year (line 24a page 1)		
20. TOTAL (lines 18 and 19)		
21. Expenditures during year (line 21a page 1)		
22. Other adjustments - specify		
23. TOTAL (lines 21 and 22)		
24. Balance at end of year (line 20 less line 23)	-0-	
25. UNAPPROPRIATED FUND:		
26. Balance at beginning of year	308,372	
27. Increase or decrease during year (line 25 or 26 page 1)	26,774	
28. Balance at end of year (lines 26 and 27)	335,146	
29. TOTAL general fund balances (lines 24 and 28)		335,146
30. TOTAL (lines 10 to 15 and line 29)		\$ 708,384

CERTIFICATION BY CHARITABLE ORGANIZATION

We certify that the information furnished in this financial report, including continuation sheets, is true and correct to the best of our knowledge.

Paul E. Frank
Signature of President or Authorized Officer

Executive Vice President

Title

Date Signed

James A. Shannon
Signature of Chief Fiscal Officer - STAFF

Associate Executive Director

Title

Date Signed

STATE OF INDEPENDENT ACCOUNTANTS

We have examined the balance sheets of Epilepsy Foundation of America as of December 31, 1975 and the related summary of financial activities for the year then ended attached to this report. Our examination was made in accordance with generally accepted auditing standards and accordingly included such tests of the accounting records and such other auditing procedures as we considered necessary in the circumstances as further described in the following paragraph.

It was impracticable for us to extend our examination of contributions received from the public beyond examining the sources as represented. The accompanying statement does not include the amounts of individual organizations.

As described in Paragraph 4, Epilepsy Foundation of America changed its method of compiling income from public contributions as of December 31, 1974.

In our opinion, the accompanying balance sheets and summary of financial activities present fairly the financial position of Epilepsy Foundation of America as of December 31, 1975, the changes in the fund balances and the results of its operations for the year then ended, in conformity with generally accepted accounting principles which, except for the change described in paragraph 4, have been applied on a basis consistent with that of the preceding year and are in the free capital by the State of Pennsylvania.

Our examination was made primarily for the purpose of forming our opinion on the financial statements referred to in the preceding paragraph taken as a whole. We also examined the analysis of functional expenditures, included in this report, by similar auditing procedures. In our opinion, this supplementary information, which is not audited by a fair presentation of financial position and results of operations, is stated fairly in all material respects in relation to the financial statements taken as a whole.

We are independently engaged to the practice of public accounting and are located at 2001 K Street, N. W., Washington, D. C.

Signature *Paul A. Shannon*

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February 25, 1974

Epilepsy Foundation of America
1828 L. Street, N.W.
Washington, D.C. 20036

Dear Sir:

We have examined your application for a registration under the Solicitation of Charitable Funds Act as amended.

The application indicates that the fund-raising expenses for your organization are 41 percent of total public support received.

Since the Solicitation of Charitable Funds Act provides that no applicant shall be approved if fund-raising costs exceed 35 percent, the renewal application of the Epilepsy Foundation of America is denied.

Until a new application is received which is found to be in accordance with the provisions of the statute, your group is prohibited from soliciting funds in the Commonwealth.

I want you to be aware that Section 3 (a.1) of the Act provides that any applicant who is denied registration may, within 15 days from the date of notification of such denial, request in writing, a hearing before the Commission; that hearing, in turn, must be held within 15 days from the date of the request.

And, that Section 6 (a.1) provides that in the event special facts or circumstances are presented showing justification for expenses higher than 35 percent, the Commission has the discretion to allow

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Epilepsy Foundation of America
February 25, 1974

such higher expenses and may impose such conditions
as the Commission or the Secretary of the Commonwealth
deem necessary for such exemption.

Very truly yours,

Carol Cochran
Director

jbl:CC

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Washington, D.C. 20036

DEPARTMENT OF STATE

Ms. Carol Cochran
Director
Commission on Charitable
Solicitations
Department of State
Commonwealth of Pennsylvania
Harrisburg, Pennsylvania 17120

March 13, 1974

Re: Epilepsy Foundation of America
Application for Certificate of Registration
and Annual Report

Dear Ms. Cochran:

I wrote you on February 1, 1974 and enclosed therewith an application and annual report on behalf of the Epilepsy Foundation of America for which I am General Counsel. You replied directly to the Foundation by letter dated February 25, 1974 which was received on March 1, 1974.

You indicated in your letter a denial of the application on the grounds that the fund raising costs exceed 35%.

On behalf of the Foundation I would request a stay of the denial until we have an opportunity to be heard by the Commission on Charitable Organizations. I would request a copy of the rules and regulations of the Commission as set forth under Section 5 (b) of Act #337 of 1963 as amended by Act #246 of 1972, and the appropriate administrative agency Act of the Commonwealth of Pennsylvania.

We, on behalf of the Foundation, will obviously want to appeal the to grant refusal by the Director of the Commission on Charitable Organizations the application of the Epilepsy Foundation of America. I believe that the Commission should examine on the following basis:

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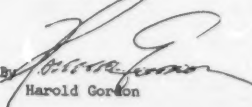
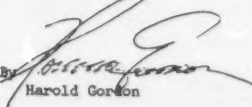
1. That we did, in fact, show specific circumstances as set forth in Section 6 (a.1) of the Pennsylvania Solicitation of Charitable Funds Act showing special facts or circumstances for expenses higher than 35%;

2. That in a situation where a consolidated return is filed showing the fund raising ratio to be less than 35%, then an application may be approved.

I would appreciate it that if a formal appeal is to be filed with the Commission on Charitable Solicitations, that this letter be taken as a request for such an appeal.

Very truly yours,

GORDON & HEALY


By 
Harold Gordon

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CCO-1 2a-15-72

PART I

ANNUAL REPORT

EX-14

Page 1

For Year Ended Dec. 31 1972

Legal Name of Organization Epilepsy Foundation of America and AffiliatesNumber and Street 1828 L Street, N.W.City and State Washington, D. C.Zip Code 20036

SUMMARY OF FINANCIAL ACTIVITIES

Enter "none" next to those items which are not applicable to the organization's financial activities.

PUBLIC SUPPORT AND REVENUE

1. Contributions (including \$ received in kind)	\$3,441,621
2. Capital funds campaign (including \$ received in kind)	16,751
3. Special events (after deducting \$ 21,662 for direct expenses)	39,396
4. Endowment gifts and bequests	11,000
5. Bequests other than endowments	124,922
6. TOTAL received directly (lines 1 to 5)	3,633,690
7. Indirect public support (Schedule A, page 2)	165,879
8. TOTAL public support (lines 6 and 7)	3,799,569
9. Fees and grants from government agencies	280,340
10. Other revenue (Schedule B, page 2)	67,253
11. TOTAL public support and revenue (lines 8 to 10)	4,147,162
12. Support and grants limited by donors or grantors (Schedule C, page 2)	503,062
13. Support and revenue available to finance current general activities (line 11 less line 12)	\$3,644,100

EXPENDITURES AND APPROPRIATIONS TO SPECIAL FUNDS

14. Program services (identify by name):		
(a) Research	\$ 176,004	
(b) Public Health Education	364,161	
(c) Professional Education and Training	188,019	
(d) Community Services	1,059,536	
(e) Patient Services	318,029	
(f) TOTAL (lines 14a to e)		2,105,749
15. Management and general	\$ 611,797	
16. Fund-raising: (a) General support	\$1,365,107	
(b) Capital funds campaign		
(c) TOTAL (lines 16a and b)	1,365,107	
17. TOTAL supporting services (lines 15 and 16c)		1,976,904
18. Major property and equipment acquisitions		52,819
19. Payments to affiliated organizations		
20. TOTAL expenditures (lines 14f, 17, 18 and 19)		4,135,472
21. Deduction of expenditures financed by special funds:		
(a) Special purpose funds	\$	
(b) Current restricted funds	414,407	
(c) Land, building and equipment funds		
(d) Funds functioning as endowment		
(e) TOTAL (lines 21a to d)		414,407
22. Expenditures financed by current general revenue (line 20 less line 21e)		3,721,065
23. Excess of (a) current general revenue over expenditures (line 13 less line 22), or		
(b) expenditures over current general revenue (line 22 less line 13)		76,965
24. Deduction of appropriations by board:		
(a) To special purpose funds	\$	
(b) To land, building and equipment funds		
(c) To funds functioning as endowment		
(d) TOTAL (lines 24a to c)		
25. Increase in unappropriated current general fund (line 23a less line 24d), or		\$
26. Decrease in unappropriated current general fund (line 24d less line 23a or line 23b plus line 24d)		\$ 76,965

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Schedule A — INDIRECT PUBLIC SUPPORT

Schedule B — OTHER REVENUESchedule C—SUPPORT AND GRANTS LIMITED BY DONORS OR GRANTORS

ANALYSIS OF FUNCTIONAL EXPENDITURES

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Page 4

CURRENT GENERAL FUND BALANCE SHEET

ASSETS

1. Cash	\$ 621,838
2. Accounts receivable (less allowance for uncollectible accounts of \$)	78,104
3. Pledges receivable (less allowance for uncollectible pledges of \$) of receipt	
4. Marketable securities, at cost or market value at date /	73,731
5. Inventory of mailing & educational materials, at cost	69,283
6. Prepaid expenses	19,068
7. _____	
8. _____	
9. TOTAL (lines 1 to 8)	\$ 862,022

Liabilities and Fund Balance

10. Accounts payable	\$ 372,596
11. Accrued expense	32,493
12. Due to restricted funds	8,201
13. _____	
14. _____	
15. _____	
16. Fund balance:	
17. SPECIAL PURPOSE FUNDS:	
18. Balance at beginning of year	\$ _____
19. Appropriated during year (line 24a page 1)	_____
20. TOTAL (lines 18 and 19)	_____
21. Expenditures during year (line 21a page 1)	_____
22. Other adjustments — specify _____	_____
23. TOTAL (lines 21 and 22)	_____
24. Balance at end of year (line 20 less line 23)	_____
25. UNAPPROPRIATED FUND:	
26. Balance at beginning of year	525,697
27. Increase or decrease during year (line 25 or 26 page 1)	(76,965)
28. Balance at end of year (lines 26 and 27)	448,732
29. TOTAL general fund balances (lines 24 and 28)	448,732
30. TOTAL (lines 10 to 15 and line 29)	\$ 862,022

CERTIFICATION BY CHARITABLE ORGANIZATION

We certify that the information furnished in this financial report, including continuation sheets, is true and correct to the best of our knowledge.

James E. French
Signature of President or Authorized Officer

Eric White Vice President 3/5/74
Title Date Signed

Thomas A. Neal
Signature of Chief Fiscal Officer

Thomas 3/5/74
Title Date Signed

REPORT OF INDEPENDENT ACCOUNTANTS

We have examined the combined balance sheets of Epilepsy Foundation of America and affiliates as of December 31, 1973 and the related combined summary of financial activities for the year then ended contained in this report. Our examination was made in accordance with generally accepted auditing standards and necessarily included such tests of the accounting records and such other auditing procedures as we considered necessary in the circumstances as further described in the following paragraph.

It was impracticable for us to extend our examination of contributions received from the public beyond ascertaining the amounts so recorded.

As described in Note 2, Epilepsy Foundation of America changed its method of recognizing revenue from public contributions as of December 31, 1973.

In our opinion, the accompanying combined balance sheets and combined summary of financial activities present fairly the financial position of Epilepsy Foundation of America and affiliates at December 31, 1973, the changes in fund balances and the combined results of their operations for the year then ended, in conformity with generally accepted accounting principles which, except for the change (with which we cannot) referred to in the preceding paragraph, have been applied on a basis consistent with that of the preceding year and are in the form required by the State of Pennsylvania.

The analysis of functional expenditures presents expenditures for programs and supporting services in total amounts. As described in Note 3, amounts by object classification are not available for 1973 for the combined expenditures of Epilepsy Foundation of America and affiliates.

We are independently engaged in the practice of public accounting and are located at 1800 K Street, N.W., Washington, D. C.

Signature *Eric White*
Date APRIL 9, 1974

PART II

ANNUAL REPORT

Page 1

December 31, 1972
(Date)

SUPPLEMENTARY BALANCE SHEETS

Legal Name of Organization Epilepsy Foundation of AmericaNumber and Street 1828 Street, N.W.City and State Washington, D.C.Zip Code 20036

Schedule A—RESTRICTED FUNDS

Assets

1. Cash		\$ 183,604
2. Accounts receivable	receipt	5,530
3. Marketable securities, at cost or market value at date of /		29,808
4. Due from General Fund		8,201
5. TOTAL restricted (lines 1 to 4)		\$ 227,143

Liabilities and Fund Balance

6. Accounts payable		\$ 3,074
7. Unearned income from state and federal government grants		49,930
8.		
9. Fund balance — beginning of year	\$ 113,235	
10. Received during year (Part I, Schedule C, line 1)	475,311	
11. TOTAL (lines 9 and 10)	588,546	
12. Expenditures during year (Part I, Page 1, line 21b)	414,407	
13. Other adjustments — specify —		
14. Fund balance — end of year (line 11 less lines 12 and 13)		174,139
15. TOTAL restricted (lines 6 to 8 and 14)		\$ 227,143

Schedule B—ENDOWMENT FUNDS AND FUNDS FUNCTIONING AS ENDOWMENT FUNDS

Assets

1. Cash		\$ 12,800
2. Investments		
3.		
4.		
5.		
6.		
7. TOTAL endowment funds and funds functioning as endowment (lines 1 to 6)		\$ 12,800

Liabilities and Fund Balance

8.			\$
9.			
10.			
	Endowment Funds (a)	Funds functioning as endowment (b)	
11. Fund balances — beginning of year	\$ 1,800	\$	
12. Endowment gifts and bequests (Part I, Page 1, line 4)	11,000		
13. Appropriated during year (Part I, Page 1, line 24c)			
14. Gain on investments			
15. TOTAL (lines 11 to 14)	12,800		
16. Expenditures during the year (Part I, Page 1, line 21d)			
17. Other adjustments — specify			
18. Less on investments			
19. TOTAL (lines 16 to 18)			
20. Fund balances — end of year (line 15 less line 19)	12,800		
21. Total endowment funds and funds functioning as endowment (lines 8 to 10, 20(a) and 20(b))			\$ 12,800

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Schedule C — LAND, BUILDINGS AND EQUIPMENT FUNDS

UNEXPENDED FUNDS

Assets

1. Cash	\$ 14,461
2. Marketable securities —	
3. Pledges receivable (less allowance for uncollectible pledges of \$	
4.	
5.	
6. TOTAL unexpended funds (lines 1 to 5)	\$ 14,461

Liabilities and Fund Balance

7. Accounts payable	\$	
8.		
9. Fund balance — beginning of year	\$ 5,203	
10. Received during year (Part I, Schedule C, line 2)	16,751	
11. Appropriated during year (Part I, Page 1, line 24b)		
12. TOTAL (lines 9, 10 and 11)		\$ 21,954
13. Transferred to equity in land, building and equipment fund	7,493	
14. Capital funds campaign expenditures (Part I, Page 1, line 16b)		
15. Other adjustments — specify		
16. TOTAL (lines 13, 14 and 15)		7,493
17. Fund balance — end of year (line 12 less line 16)		14,461
18. TOTAL unexpended funds (lines 7, 8 and 17)		\$ 14,461

EQUITY IN LAND, BUILDINGS AND EQUIPMENT

Assets

19. Land — and buildings	\$ 103,219
20. Improvements other than buildings —	7,284
21. Buildings —	
22. Furniture and equipment —	115,803
23. Automobiles	
24. Less: Accumulated depreciation	(36,278)
25. TOTAL investment (lines 19 to 24)	\$ 190,028

Liabilities and Fund Balance

26. Mortgages payable	28,250
27.	
28.	
29. Fund balance — beginning of year	\$ 117,628
30. Transferred from unexpended funds	7,493
31. TOTAL (lines 29 and 30)	52,819
32. Depreciation for the year	16,162
33. Disposals or write-offs	
34. Other adjustments — specify	
35. TOTAL (lines 32, 33 and 34)	16,162
36. Fund balance — end of year (line 31 less line 35)	161,778
37. TOTAL investment (lines 26, 27, 28 and 36)	\$ 190,028

EPILEPSY FOUNDATION OF AMERICA AND AFFILIATESNOTES TO FINANCIAL STATEMENTSDECEMBER 31, 19721. Organization and Accounting

The Epilepsy Foundation of America (EFA) is a non-profit organization incorporated under the laws of the State of Delaware and was established to promote research into the causes and treatments of epilepsy, to support education and vocational programs for persons with epilepsy and to provide educational information about epilepsy to the general public.

EFA has been granted an exemption from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. In addition, the Internal Revenue Service has ruled that EFA is a public foundation.

The accompanying financial statements have been prepared in accordance with standards adopted by the National Health Council and the National Social Welfare Assembly. The combined financial statements include the accounts of EFA and its affiliated local chapters. Donated assets are recorded at their fair market value at the date of gift and depreciation of buildings, leasehold improvements and equipment is recorded by a direct charge to the Land, Building and Equipment Fund (such assets are being depreciated using the straight-line method over their estimated useful lives of 5 to 20 years). Fixed assets acquired by the General and Restricted Funds are treated as transfers to the Land, Building and Equipment Fund.

2. Change in Accounting Method

EFA has changed its method of accounting for mail contributions to recognize as income in 1972 contributions received in 1973 which had been mailed, based on postmarks, on or before December 31, 1972. This change was made to relate EFA's income recognition to the period in which the contributions were actually made and to avoid the effects of mail delays during the holiday period. This change resulted in the recognition of additional revenue of approximately \$71,000 in 1972. It is not possible to determine the effect such a change would have had on years prior to 1972.

3. Retirement Plan

Effective November 1, 1972, EFA (National Office) adopted a contributory retirement plan covering substantially all employees. Retirement plan benefits are to be paid by a Group Annuity Contract with an insurance company. The total pension expense for 1972 was \$4,410 which includes amortization of unfunded prior service costs over thirty years. The excess of the actuarially computed value of vested benefits as of December 31, 1972 exceeded the total of the pension fund and balance sheet accruals by approximately \$68,000.

4. Lease Commitments

EFA (National Office) leases office space for annual rental payments of \$45,000 under a lease agreement extending through September, 1976. In addition, EFA leases regional office space for aggregate annual rental payments of approximately \$8,400.

5. Analysis of Combined Functional Expenditures

The analysis of Combined Functional Expenditures presents expenditures for program and supporting services in total amounts. The amounts by object classification for each service for the combined expenditures are not available because the affiliates did not report such information to EFA (National Office).

EX. #5

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EPILEPSY FOUNDATION OF AMERICA

Fund-raising costs, 1970 application, 1969 fiscal report: 55.42 %

"	1971	"	, 1970	"	"	:	48.11%
---	------	---	--------	---	---	---	--------

"	1972	"	, 1971	"	"	:	41.98%
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EX. #6

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IN THE
COMMONWEALTH COURT OF PENNSYLVANIA

EPILEPSY FOUNDATION OF AMERICA :

:

:

v. :

NO. 403 C.D. 1974

:

THE COMMISSION ON CHARITABLE
SOLICITATIONS :O R D E R

AND NOW, this 29th day of March, 1974, upon
consideration of the motion and argument of Counsel for the
Commonwealth made in open court to quash the above-captioned
appeal as premature and the argument of Counsel for the
Petitioner contra, the motion is granted, and for that sole
reason the petition for supercedeas is dismissed.


JAMES C. CRUMLISH, JR., Judge

CERTIFIED FROM THE RECORD

APR 1 1974

Francis C. Barbush
CHIEF CLERK

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IN THE COMMONWEALTH COURT OF PENNSYLVANIA

EPILEPSY FOUNDATION OF AMERICA :

:

: NO.

VS. :

:

THE COMMISSION ON CHARITABLE
SOLICITATIONS: Appeal from denial of renewal
: application to solicit con-
: tributions in PennsylvaniaPETITION TO APPELLATE COURT FOR SUPERSEDEAS

TO THE HONORABLE THE JUDGES OF THE SAID COURT:

1. On February 25, 1974, without notice and hearing, the Director of The Commission on Charitable Solicitations ("Commission") by letter denied the renewal application of Epilepsy Foundation of America ("Foundation").

2. Thereafter, Foundation requested a hearing on its renewal application, which hearing was held in Harrisburg on March 26, 1974 before the Commission with five (5) members initially participating and ultimately, when a decision was rendered, four (4) members participating. The Commission is composed of seven (7) members.

3. At the conclusion of the hearing, the designate of the Secretary of State, Ronald Pettine, acting as Chairman, announced that the renewal application of the Foundation was denied. Attached hereto, made a part hereof and marked Exhibit "A" is an affidavit in support of the averments by Louis D. Apothaker, Esquire, co-counsel for the Foundation who participated at the aforementioned hearing before the Commission.

4. The purported reason for the denial of the Foundation's renewal application was that the solicitation and fund raising expenses were in excess of thirty-five (35%) per cent of total monies received by reason of any solicitation and/or fund raising activities or campaigns.

5. The Foundation's principal fund raising activity is through mail solicitation. The Foundation engages no professional fund raisers.

6. The Commission has the discretion to grant a license to a charitable organization to solicit funds if there are presented special facts or circumstances showing that expenses higher than thirty-five (35%) per cent are not unreasonable.

7. Because the Foundation utilizes nation-wide, computerized mailing lists in its solicitation, should the Foundation's license not be renewed in Pennsylvania, it would be necessary for the Foundation to engage personnel to sort and remove all mailings for Pennsylvania, thereby increasing substantially the cost of solicitation.

8. The Foundation has recently embarked on a program of establishing active local chapters in the hope and anticipation that this will further publicize the work of the Foundation, thereby ultimately reducing the cost of fund raising and solicitation.

9. In 1972, the percentage representing the cost of fund raising and solicitation by the Foundation was 40.6%, as computed by the Commission.

10. In 1972, the percentage representing the cost of fund raising and solicitation by the Foundation and affiliated chapters was 35.9%, as computed by the Commission, and 32.9% as computed by the Foundation.

11. On March 27, 1974, an appeal has been filed with the Commonwealth Court simultaneously with the filing of this Petition for Supersedeas.

12. Unless the Court grants this Petition for Supersedeas, which supersedeas will permit the Foundation to continue to solicit funds pending ultimate disposition of the appeal, the Foundation will be irreparably harmed. The granting of a supersedeas will in no way prejudice the Commission or any of the citizens of Pennsylvania.

WHEREFORE, your petitioner prays that an Order be entered permitting the Epilepsy Foundation of America to continue to solicit funds pending final disposition of this appeal.

BLANK, ROME, KLAUS & COMISKY

BY:

Leonard Dubin
LEONARD DUBIN

COMMONWEALTH OF PENNSYLVANIA :
COUNTY OF PHILADELPHIA : ss
:

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LOUIS D. APOTHAKE, being duly sworn according to law, deposes and says that he is a partner in the law firm of Blank, Rome, Klaus & Comisky and that in that capacity he participated as co-counsel for Epilepsy Foundation of America ("Foundation") at a hearing before The Commission on Charitable Solicitations ("Commission") conducted on March 26, 1974, the purpose of which was to hear testimony on the renewal application of the Foundation; that at the conclusion of the hearing, after the court reporter had left, Ronald Pettine announced that the Commission denied the Foundation's renewal application; and that Richard Orloski, sitting as the designate of the Attorney General on the Commission, announced that he would immediately seek a temporary restraining order from the Commonwealth Court prohibiting the Foundation from soliciting funds; and that the facts set forth in the within Petition are true and correct to the best of his knowledge, information and belief.

Louis D. Apothaker
LOUIS D. APOTHAKE

Sworn to and subscribed
before me this 27th day
of March, 1974.

Beatrice K. Leaden
Notary Public

Notary Public, Philadelphia, Philadelphia Co.
My Commission Expires January 27, 1975

EXHIBIT "A"

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C. Cooper

COMMISSION ON CHARITABLE ORGANIZATIONS :
 DEPARTMENT OF STATE :
 COMMONWEALTH OF PENNSYLVANIA :

IN THE COMMONWEALTH COURT
 OF PENNSYLVANIA

VS.

NO. 422 20 1974

THE EPILEPSY FOUNDATION OF AMERICA

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APR 1 1974

ORDER

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RECEIVED

AND NOW, this 29th day of March, 1974,

upon consideration of the Epilepsy Foundation of America's
 Petition for Supersedeas, and after oral argument, it is hereby
 ORDERED AND DECREED that the Order of the Commission on Charitable
 Organizations denying the renewal application of the Epilepsy
 Foundation of America is stayed, and the Epilepsy Foundation of
 America is permitted to solicit funds and engage in fund raising
 activities in the Commonwealth of Pennsylvania pending final
 disposition of the appeal in this matter.

BY THE COURT:

RECEIVED FROM THE CLERK

APR 1 1974

Francis C. Barber
 CHIEF CLERK

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